

# Michigan Arthritis Action Plan



## A Strategic Plan to Reduce the Burden of Arthritis in Michigan

Michigan Department of Community Health  
Arthritis Foundation Michigan Chapter  
University of Michigan

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May 4, 2001

James K. Haveman, Jr., Director  
Michigan Department of Community Health  
Lansing, Michigan 48913

Dear Mr. Haveman:

It is with considerable pride that we present to you and to the people of the State of Michigan the *Michigan Arthritis Action Plan*. Arthritis and other rheumatic conditions are among the most common chronic disease conditions and are the leading cause of disability in the United States. As Michigan moves into the new millennium, the aging of our population is expected to result in increasing rates of osteoarthritis among Michigan citizens.

Arthritis is not just a condition of the elderly, however. Thousands of Michigan children and those in mid-life suffer from one of more than 100 forms of arthritis. Fortunately, we have learned a great deal about arthritis in recent years – about its manifestations in our population and about how we can prevent or reduce its consequences in people of all ages.

Michigan owes a considerable debt to the 25 *Michigan Arthritis Action Plan* Steering Committee members who worked diligently over the last nine months to produce this plan. The *Michigan Arthritis Action Plan* (MAAP) was developed through a four-step, strategic-planning process including 1) in-depth reviews of the 1999 *National Arthritis Action Plan* as well as reviews of current Michigan programs, policies and health plans related to arthritis; 2) a series of regional discovery meetings throughout the state with presentations from people with arthritis, programs, business interests, health providers and community leaders; 3) a broadly-representative scientific forum and recommendation prioritization process hosted by the University of Michigan, MDCH and the Arthritis Foundation Michigan Chapter; and 4) a final review and concurrence by the *Michigan Arthritis Action Plan* Steering Committee of draft recommendations following a public comment period. The overall process involved hundreds of Michigan citizens: persons with arthritis and their families, physicians, state and national researchers, public health officials, business and community interest groups, the Office of Services to the Aging and senior citizen programs. The resulting plan represents a practical, multi-faceted and cost-effective statewide and community-based response to this devastating condition.

The *Michigan Arthritis Action Plan* Steering Committee wishes to thank Governor Engler and the Michigan Department of Community Health for its strong support of our efforts to address this critical health problem. We remain ready to assist you in the full implementation of the recommendations in this report.

Sincerely,

*David Fox*

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University of Michigan  
Ann Arbor, Michigan  
Co-Chair, MAAP



Michelle Glazier, President/CEO  
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# Michigan Arthritis Action Plan

## Table of Contents

<b>Executive Summary .....</b>	<b>i</b>
<b>Section I: Background</b>	
A. Definition of Arthritis .....	1
B. The Arthritis Burden in Michigan .....	3
C. Development of the Michigan Plan .....	8
D. The Aims of the Michigan Plan .....	9
<b>Section II: The Plan</b>	
Part A: Michigan Arthritis Infrastructure .....	11
Part B: Programs of Intervention .....	15
Part C: Data and Research .....	24
Part D: Public Awareness, Communication and Education .....	29
Part E: Education and Communication Strategies for People with Arthritis and their Families .....	35
Part F: Communication Strategies for Health Professionals .....	40
<b>Section III: Implementation</b>	
A. Priorities for Early Implementation .....	45
B. Next Steps .....	45
Appendix A: Michigan Arthritis Action Plan Steering Committee .....	46
Appendix B: Acknowledgments .....	47
Appendix C: Participating Organizations .....	49
Appendix D: Current Arthritis Resources .....	50
Appendix E: Arthritis Exercise Classes .....	58
Appendix F: Arthritis Self-Help Course Leaders .....	59
Appendix G: Arthritis-Related Support Groups .....	60

### ACRONYMS Found in the *Michigan Arthritis Action Plan*

**AFAP:** *Arthritis Foundation Aquatic Program*, a warm water exercise program for people with arthritis  
**ASHC:** *Arthritis Self-Help Course*, a self-management course for people with arthritis  
**BRFS:** Behavioral Risk Factor Survey  
**CDC:** Centers for Disease Control and Prevention  
**JA:** Juvenile arthritis

**MAAP:** *Michigan Arthritis Action Plan*  
**MACP:** Michigan Arthritis Collaborative Partnership  
**MDCH:** Michigan Department of Community Health  
**NAAP:** *National Arthritis Action Plan*  
**OA:** Osteoarthritis  
**P.A.C.E.:** *People with Arthritis Can Exercise*, an Arthritis Foundation land-based exercise program  
**RA:** Rheumatoid arthritis  
**SLE:** Systemic Lupus Erythematosus

## **Michigan Arthritis Action Plan Executive Summary**

Arthritis and other rheumatic conditions are among the most common chronic conditions and are the leading cause of disability in the United States and in Michigan. These conditions can lead to limitations in work, recreation, home activities and basic self-care. Arthritis can result in life-threatening complications. Despite popular misconceptions, arthritis is not just a condition of the elderly nor is it just a normal part of aging. While some forms of arthritis, such as osteoarthritis, are more prevalent among older populations, arthritis impacts many more people than is commonly known. The majority of those who have arthritis are under the age of 65. Almost 15 percent of Michigan's population has or will have arthritis.

Further, arthritis generates significant health care costs. For example, in Michigan for the years 1990 to 1996, osteoarthritis (OA) was the primary cause of 91,000 hospitalizations. More than 90 percent of these hospitalizations involved joint replacement surgery. A typical hospital cost for a total knee replacement surgery in Michigan is \$15,000-\$27,000 depending upon the hospital, not including physician and rehabilitation fees. The psychological and social costs of arthritis are harder to measure. They include lost time with family members, chronic pain, loss of employment, and often a sense of helplessness and lowered self-esteem.

The process of developing the *Michigan Arthritis Action Plan* involved hundreds of Michigan citizens: persons with arthritis and their families, physicians, state and national researchers, public health officials, business and community interest groups, the Office of Services to the Aging and senior citizen programs. The four-step process included 1) in-depth reviews of the 1999 *National Arthritis Action Plan* and current Michigan arthritis programs and initiatives; 2) a series of regional arthritis discovery meetings throughout the state with invited presentations from persons with arthritis, programs, business interests, health providers and community leaders; 3) a broadly-representative scientific forum hosted by the University of Michigan Multipurpose Arthritis and Musculoskeletal Diseases Center; and 4) review and concurrence by the *Michigan Arthritis Action Plan* Steering Committee of MAAP draft recommendations. This was followed by a public comment period of 30 days on the draft plan prior to finalization.

The *Michigan Arthritis Action Plan* represents a road map of practical and effective steps that Michigan can take to prevent, manage and decrease the burden of arthritic conditions on Michigan citizens and their families. At the same time, the plan aims to reduce the unnecessary health care costs associated with arthritic conditions.

## **Key Recommendations:**

- ✓ **Establish an ongoing Michigan Arthritis Collaborative Partnership (MACP).**  
The MACP's continuing purpose will be to oversee implementation of the recommendations in the report, to identify new sources of program and financial support for arthritis programs, and to create a consensus on priorities and policies for arthritis programming in the state. The MACP will include representatives from the Arthritis Foundation Michigan Chapter, the Michigan Department of Community Health, the University of Michigan Multipurpose Arthritis and Musculoskeletal Diseases Center and other appropriate public and private organizations.
- ✓ **Increase access to effective arthritis intervention programs.**  
The MACP and its affiliated partners will work to increase the geographical distribution, acceptability and accessibility of effective exercise and wellness programs for Michigan citizens with arthritis. The plan lays out a process for greatly expanding the excellent, proven arthritis programs developed by the Arthritis Foundation so they are accessible to all people who need them in Michigan.
- ✓ **Conduct an ongoing state-wide arthritis education and public awareness campaign.**  
This campaign will provide appropriate information about arthritis by:
  - Informing the public about the nature and course of arthritis as well as treatments, interventions and the resources available to help people with arthritis.
  - Educating health professionals, human services groups and community organizations about the prevalence, health burden, and societal costs of arthritis.
  - Providing information to employers, schools, and work sites.
- ✓ **Increase public health surveillance and reporting on arthritis.**  
The plan recommends increasing the surveillance and monitoring of arthritis in Michigan including the behavioral risk factors for the conditions, the nature and extent of arthritis in Michigan, and the trends over time. The plan anticipates continued collaboration with the MDCH chronic disease and epidemiology programs to conduct surveillance, interpret data and to continue to track trend-line information and program progress. These are crucial to evaluating the effectiveness of proposed arthritis initiatives.
- ✓ **Enhance continuing professional education on arthritis topics for a variety of health care providers.**  
The MACP and associated partners will work together with Michigan's medical and allied health professional schools to increase continuing medical education about arthritis. Innovative media and Internet approaches will be used to increase the knowledge base of arthritis topics among Michigan's health professionals.

While establishing a clear vision for effective action, the *Michigan Arthritis Action Plan* is not about mandates. Its primary focus is on the achievement of what is possible, practical and worthwhile in decreasing the burden of arthritis through the mutual efforts of many partners.



## SECTION I: BACKGROUND

### A. Definition of Arthritis

"Arthritis and other rheumatic conditions are among the most common chronic conditions and the leading cause of disability in the United States. These conditions frequently lead to limitations in work, recreation, and usual activities, including basic self-care. Some types of arthritis can result in life-threatening complications. The term arthritis, as used here, encompasses more than 100 diseases and conditions affecting joints, the surrounding tissues, and other connective tissues." <sup>1,2</sup>

*National Arthritis Action Plan*

The six most common types of arthritis include:

- **Osteoarthritis (OA)** is a degenerative joint disease. It most often affects the hip, knee, foot and hand — but can affect other joints as well. Degeneration of joint cartilage and changes in underlying bone and supporting tissues can lead to pain, stiffness, movement problems and activity limitations.<sup>1</sup> Joint replacement surgery is sometimes required if mobility is significantly impaired. Almost 21 million Americans were affected by OA in 1990,<sup>3</sup> including an estimated 780,000 in Michigan.<sup>4</sup>
- **Fibromyalgia** is a pain syndrome of the muscles and muscle-attachment areas throughout the body. Common symptoms, in addition to muscle-pain, include sleep disorders, irritable bowel syndrome, fatigue and headaches. Some people with fibromyalgia also experience depression in the course of this condition. Fibromyalgia has been diagnosed in 3.7 million Americans<sup>3</sup> and an estimated 185,000 Michigan residents.<sup>5</sup>
- **Rheumatoid Arthritis (RA)** is a joint disorder characterized by persistent inflammation of the joint linings and in some cases the internal organs as well. The chronic inflammation of the joint linings can cause bone and cartilage erosion leading to joint deformities, activity limitations, joint pain and stiffness, and soft tissue swelling. Other symptoms include weakness, fever, fatigue and anemia. RA may affect connective tissue and blood vessels throughout the body, thus causing inflammation of internal organs such as the heart and lungs. Having RA

increases an individual's chance of dying from respiratory and infectious diseases. About 2.1 million people in the United States have this chronic inflammatory joint disorder,<sup>3</sup> including an estimated 80,000 in Michigan.<sup>4</sup>

- **Lupus: Systemic Lupus Erythematosus (SLE)** is a chronic condition that often begins with unexplained fever, fatigue, inflamed joints, sensitivity to light and rashes. In about half of individuals with lupus, severe involvement of the kidneys or nervous system develops. The incidence of SLE has markedly increased in non-white populations and women of child-bearing age. At least 239,000 Americans have suspected or diagnosed SLE,<sup>3</sup> including an estimated 9,000 in Michigan.<sup>4</sup>
- **Scleroderma** is a chronic disease of the connective tissue that causes thickening and hardening of the skin and, in some cases, of the internal organs, interfering with function. There are two types of scleroderma: a localized form which affects mainly the skin and frequently occurs in children, and a systemic form that affects the skin as well as internal body organs and that usually begins in adulthood. Symptoms of scleroderma include swollen hands, cold hands and feet, joint contractures, difficulty swallowing, shortness of breath, and kidney disease. Estimates of the prevalence of systemic scleroderma suggest that it affects some 250 people per million in the United States with even more people having the localized form. About 2,500 to 3,000 people in Michigan have this condition.<sup>6</sup>
- **Juvenile arthritis (JA)** comprises all childhood rheumatic conditions including juvenile rheumatoid arthritis, systemic lupus erythematosus, juvenile dermatomyositis and scleroderma. Childhood rheumatic conditions affect 285,000 children under the age of 16 in the United States.<sup>7</sup> At least 6,000 children in Michigan are estimated to have JA.<sup>8</sup>

## **B. The Arthritis Burden in Michigan**

Arthritis is an increasingly prevalent yet misunderstood public health concern. It affects one in every six Michigan residents<sup>4</sup>— approximately 1.5 million people.<sup>9</sup> Despite popular misconceptions, arthritis does not affect only the elderly, nor is it just a normal part of aging. While some forms of arthritis, such as osteoarthritis, are more prevalent among older populations, arthritis is hurting many more people than is commonly known:

- ▶ Arthritis afflicts people of all ages, races and classes.
- ▶ The majority of those who have arthritis are under the age of 65.<sup>9</sup>
- ▶ Arthritis is the number one cause of disability in the U.S.<sup>2</sup> and among the top causes of disability in Michigan.
- ▶ Arthritis and other musculoskeletal conditions were the second most common reported occupational injury in Michigan for 1990-1996.<sup>10</sup>

By the year 2020, the Centers for Disease Control and Prevention (CDC) estimates that almost 20 percent of the U.S. population will have arthritis — about 60 million people.<sup>9</sup> That translates to about 2.2 million Michigan<sup>4</sup> citizens (up from the current 1.5 million). Due to the expected increase in the prevalence of arthritis, the costs associated with arthritis are also expected to rise. In 1992 alone, arthritis cost the United States \$65 billion in medical bills and lost productivity — the equivalent of a moderate economic recession.<sup>11</sup>

Some of the economic costs for Michigan can be estimated by examining the hospitalization rates of persons with arthritis, specifically due to the most prevalent form of arthritis, osteoarthritis. For the years 1990 to 1996, osteoarthritis (OA) was the primary cause of 91,000 hospitalizations in Michigan, mostly due to OA of the knee (about 60 percent) and OA of the hip (32 percent).<sup>12</sup> More than 90 percent of these hospitalizations involved joint replacement surgery. The hospital charge for a total knee-joint replacement surgery in Michigan can range from \$15,000 to \$27,000 depending upon the hospital not including anesthesiology, physician's charges, or rehabilitation services.<sup>13</sup>

Between 1990 and 1996, Michigan hospitalizations due to OA rose 58 percent (from 10,627 to 16,900 per year). The majority of these patients were over the age of 60.<sup>12</sup> Due to the aging of the baby boomer population, hospitalization rates due to OA are expected to rise.

Even without age as a factor, however, the rate of hospitalizations due to knee OA still increased among the general population. Knee OA hospitalizations increased 70 percent (from 63.5 to 108.4 per 100,000) between 1990 and 1996.<sup>12</sup>

## **Michigan Arthritis Action Plan**

The growing prevalence of arthritis and its associated costs are alarming by themselves. However, the physical, psychological and social costs of the condition are also enormous:

<b>Physical Costs</b>	People with arthritis in its many forms report ongoing pain in varying degrees, from sharp, acute pain to constant dull aching — often over their lifetimes. Loss of joint motion, decreased mobility and fatigue are also common symptoms. These symptoms make it difficult for many people with arthritis to maintain a level of physical activity equal to or close to that of the rest of the adult population. Due to this decreased activity, people with arthritis are at greater risk for other diseases and conditions including heart disease, diabetes, high blood pressure, pneumonia and other infections, obesity, depression, and anxiety. Complications from some forms of arthritis, like RA, can lead to premature death.
<b>Psychological Costs</b>	Most research indicates that persons with musculoskeletal conditions experience a higher level of psychological distress than the general population, comparable with other individuals experiencing chronic illnesses. <sup>11</sup> Anxiety, depression and feelings of helplessness and low-self-esteem are common responses of persons struggling to cope with arthritis.
<b>Social Costs</b>	People with arthritis often experience decreased community and family involvement. Because of their illness, these individuals often report a loss of time with family members. In addition, many lose their jobs or are forced to reduce their hours of employment. They also may experience a general lack of understanding and compassion from others including co-workers, teachers, neighbors, friends and even health care professionals about their condition.

A national study assessing behavioral risk factors in relation to health, the Behavioral Risk Factor Surveillance Survey, reveals that the people who self-report arthritis have a substantially lower quality of life than those without arthritis.<sup>14</sup> Those with arthritis are three times more likely to report having only fair or poor health than those without arthritis. No meaningful price tag can be attached to the losses that poor health can cause in a person's own life.

Despite its negative impact on quality of life and community involvement, arthritis continues to go undiagnosed and untreated in many persons. According to interviews of participants in a 1998 study published by the CDC, 40 percent of the people who reported joint stiffness and aches had not had their arthritis diagnosed by a doctor.<sup>15</sup>

## ***Michigan Arthritis Action Plan***

The same study indicated that up to 53 percent of those who had been diagnosed with arthritis did not know what type among the 100-plus conditions they had. Inadequate medical information and lack of diagnosis are serious barriers to arthritis interventions and treatments.

Education and awareness are crucial in lessening the burden of arthritis statewide. Some forms of arthritis, such as gout, Lyme Disease and infectious arthritis are completely treatable and often curable. For other forms of arthritis, such as rheumatoid arthritis and juvenile arthritis, early diagnosis and treatment can make the difference between being permanently disabled or being able to function productively. If people do not know that help is available, they may continue to suffer needlessly, limit their employment opportunities and greatly decrease the quality of their lives.

Many arthritis patients say, "But, there's nothing I can do! I just have to learn to live with the pain." This is a common myth among people with arthritis. Even with incurable and extremely painful forms of arthritis, action can be taken to lessen the pain and to increase one's quality of life. As the Arthritis Foundation says, "take control ... we can help."

# LIVING WITH ARTHRITIS IN MICHIGAN

## Marvin Vander Velde

Marvin Vander Velde of Grand Rapids says that lifting 32,000 pounds a day is what injured his back and contributed to his osteoarthritis. Yet, he does not complain.

"I needed a job," Vander Velde says.

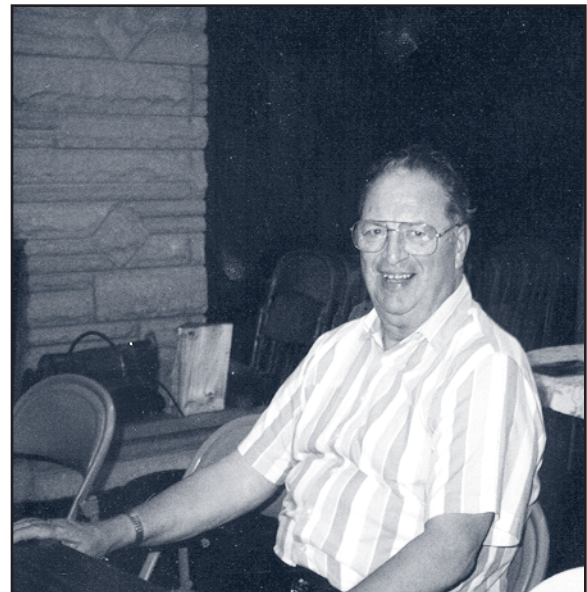
The now-retired and disabled Vander Velde worked at a factory during the Depression, transporting bundles from one conveyer belt to another. He would pick up 40-pound bundles in his arms, twist his torso, and set them on another conveyer belt. He repeated this action 800 times a day for four years.

By age 20, the hard-working young man was experiencing severe lower back pain. By his thirties, Vander Velde had to have back surgery to help him stand up straight. Despite the surgery and transferring to a less strenuous job, Vander Velde still continued to have back pain.

Vander Velde participated in physical therapy after his surgery and found it very therapeutic. The physical therapists used heat and massage to help relax the muscles in Vander Velde's back. He says that he left physical therapy feeling like he was 7 feet tall. The effect lasted part way through the day. Physical therapy is worth it to feel that good and to have a break from the pain, Vander Velde says. Eventually insurance would only pay for so many visits, however, and he had to stop.

Vander Velde is not one to give up easily, however. He took the strategies he learned at physical therapy and applied them at home, using heating pads on his back to help with the pain. Eventually Vander Velde received a back brace to help support his lower back. Despite his best efforts, Vander Velde finally had to retire early on disability because of his back injury and pain. He could not undo what years of trauma had done to his back. Vander Velde is pleased that the Michigan Arthritis Action Plan includes prevention efforts aimed at Michigan work sites to guard against repetitive joint trauma.

Since his early retirement 21 years ago, Vander Velde has been participating in warm water exercise classes at Mary Free Bed Hospital to ease his pain. It does not cure it, he says, but it allows him to be more mobile. Since Vander Velde's wages decreased when he retired, the low cost of the class is what makes it an option for him. Besides, Vander Velde says "the exercise is tremendously beneficial." He also enjoys the company of others with arthritis like himself. It brings him support and companionship.



Marvin Vander Velde

Vander Velde still takes about four or five pain killers a day for the pain he can't relieve through exercise, heat or special pillows. However, he is adamant that he does not want to complain about it anymore. "You can't sit and sing the blues all day," Vander Velde says.

"I have a lot of things that I would rather think about than my aches and pains. I can't walk, but I can talk," he says. The 78-year-old Vander Velde facilitates a marketplace ministry through his church and listens to others share their problems.



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## **C. Development of the Michigan Plan**

The *Michigan Arthritis Action Plan* (MAAP) was developed through a four-step, strategic-planning process over a six-month period. The process was overseen by the 25-member *Michigan Arthritis Action Plan* Steering Committee. Hundreds of Michigan citizens were involved: persons with arthritis and their families, physicians, state and national researchers, public health officials, business and community leaders, the Office of Services to the Aging, and senior citizen programs. The process included four planning steps:



Concerned citizens speak out at the regional arthritis discovery meeting in Gaylord.

1. In-depth reviews were conducted of the 1999 *National Arthritis Action Plan*, current Michigan programs and initiatives, and historical policies and health plans related to arthritis.
2. A series of three regional arthritis discovery meetings were held throughout the state with invited local presentations from persons with arthritis, arthritis program representatives, business spokespersons, health providers, and community leaders.
3. A broadly-representative scientific forum was hosted by the University of Michigan Multipurpose Arthritis and Musculoskeletal Diseases Center, MDCH and the Arthritis Foundation, Michigan Chapter. At the forum, the latest scientific research concerning arthritis was presented. In addition, the MAAP Steering Committee reviewed the input from the regional arthritis discovery meetings, the status of existing programs, the results of previous planning efforts, and scientific research. Possible recommendations were identified and prioritized.
4. Specific recommendations were finalized by the *Michigan Arthritis Action Plan* Steering Committee and subjected to a public comment period of 30 days. The steering committee reviewed all public comments prior to finalization and distribution of the plan.

At each stage in the process, efforts were made to obtain the broadest possible participation from individuals and families affected by arthritis. News releases, an Internet posting, personal invitations and professional networks were all used to get the best possible input during the preparation of the plan.



## **D. The Aims of the Michigan Plan**

In 1999, the first *National Arthritis Action Plan* was published — presenting a vision for reducing the burden of arthritis in the United States. The overall intent of the *Michigan Arthritis Action Plan* is to provide a framework for implementing the national plan in Michigan, taking into account Michigan's unique challenges and resources. The plan employs strategies identified as realistic by Michigan health care experts, consumers and industry representatives.

The MAAP is a practical, achievable, three-to-five-year road map to respond to the problem of arthritis in Michigan. It recognizes that no single agency, state department or program can do what is necessary to reduce the burden of arthritis in Michigan. Rather, it proposes a specific goal of identifying those partners and collaborators who can and will work together to achieve full implementation of the recommendations. In a very real sense, it is what Michigan — all of us — should do. The MAAP, therefore, has four specific aims:

1. To build public awareness of arthritis as the leading cause of disability and as an important public health issue;
2. To provide a clear, concise, road map of what can and must be done to reduce the burden of arthritis in Michigan;
3. To promote the partnerships, collaborations and commitments necessary to effectively implement the recommendations;
4. To build the framework necessary to carefully promote, monitor and evaluate the best practices for the prevention, diagnosis, treatment, and management of arthritis.

Ultimately, the success of this plan must be judged by the effectiveness of its recommendations in preventing arthritis, minimizing pain and disability due to arthritis, and supporting patients and families with the resources they need to cope with arthritis.



## **SECTION II: THE PLAN**

### **A. Michigan Infrastructure and Guidelines for Arthritis**

#### **Introduction and Statement of Problem:**

Arthritis is the leading cause of disability in the United States and affects 1.5 million Michigan citizens. Presentations at the regional arthritis discovery meetings demonstrated that high quality, affordable programs and services are available to people with arthritis but only in some areas of the state. In addition, persons with arthritis and their health care providers report numerous financial, geographic, and educational barriers to obtaining comprehensive arthritis care. Arthritis Steering Committee members overwhelmingly agreed that a Michigan-specific infrastructure and program delivery guidelines are needed to help eliminate these barriers if arthritis is to be addressed as a public health issue.

#### **Recommendations for Infrastructure and Guidelines**

**Recommendation 1: Michigan must establish an ongoing Michigan Arthritis Collaborative Partnership (MACP) by 2001, to establish the necessary infrastructure and guideline framework for implementing the MAAP.**

Michigan should maintain the new collaborative relationships developed during the process of drafting the MAAP by establishing an ongoing collaborative partnership. The MACP will oversee the implementation of the recommendations in this report, identify new sources of financial support for arthritis programs, and achieve consensus on priorities for arthritis programming in the state. At a minimum, the MACP should include representatives from the Arthritis Foundation, Michigan Chapter; the Michigan Department of Community Health; the University of Michigan Multipurpose Arthritis and Musculoskeletal Diseases Center; and other appropriate public and private organizations. The MACP must set specific time lines for recommendations 3c, 4, 5d, 8, 9, 10, 11, 12, 13, 15, 16, and 17 by the end of the first year.

"Michigan's arthritis action plan must be more than just another document that collects dust on book shelves across the state. There can be little doubt that a committed working partnership and adequate staff support is necessary if Michigan is to meaningfully address the overwhelming human and medical burden of these all-too-often disabling conditions."

Marshall Katz, MD  
Michigan Association of Health Plans

**Recommendation 2: The MACP should establish issue-specific working committees, drawing in additional partners as appropriate, to address the following issues within the next 24 months:**

**2a. Specialized Health Services**

The MACP should continue to review the status of arthritis health care services and make recommendations to eliminate barriers to the services necessary for the management of arthritis, including statewide access to: rheumatologists, pediatric rheumatologists, physical therapists, occupational therapists, podiatrists, psychologists, surgeons and other needed health professionals.

"As a practicing rheumatologist in the Upper Peninsula, I am greatly concerned that the number of specialists in rheumatology is insufficient to meet the need for the patient population. Many patients must spend a great deal of time traveling significant distances to the three rheumatologists who are available. Some forego care because access is not reasonably available."

Andrea Dlesk, MD, FACP, FACR  
U.P. Internal Medicine Associates

**2b. Rheumatologists as Principal Physicians**

The MACP, in collaboration with the appropriate professional organizations and health care systems, should establish consensus guidelines for

assigning people with complex arthritic conditions to rheumatologists or pediatric rheumatologists as their principal physicians.

### 2c. Rural Health Care Accessibility

The MACP should make recommendations to address the scarcity of rheumatologic and comprehensive arthritis care available in rural areas of Michigan, in consultation with the Michigan Center for Rural Health and the Michigan Rheumatism Society. (The Michigan Rheumatism Society is the professional association of rheumatologists in the state of Michigan).

“While rural health providers are scarce and geographically remote, increasingly, rural communities and health care providers are forming networks and integrated delivery systems. The full implementation of the Michigan Arthritis Action Plan will help to ensure that the infrastructure is available to connect rural residents with the crucial arthritis treatments and education programs they need.”

Nancy J. Struthers, MPA  
Rural Health Initiatives Coordinator  
Michigan Center for Rural Health

### 2d. Barriers to Arthritis Care

The MACP should make recommendations to lessen the barriers for persons whose economic status limits their access to arthritis health care services, self-management training and preventive interventions.

### 2e. Program and Service Infrastructures

The MACP should make recommendations to improve collaboration among community programs that deliver services and information to people with arthritis. This should include groups and individuals involved in providing health care for persons with arthritis.

## 2f. Transportation

The MACP should establish recommendations to address issues of transportation for people with arthritis throughout the state and to form linkages with disability groups and others that provide transportation services.

“There can be little doubt that thousands of Michigan citizens are not getting the services and medical care that they need simply because we have not thoroughly addressed the obvious barriers that prevent them from obtaining care. There also can be little doubt that most of these barriers could be substantially resolved with persistent effort.”

John Tower, DO  
Michigan Osteopathic Association

## **B. Programs of Intervention**

### **Introduction and Statement of Problem:**

Arthritis cannot be optimally managed and its potential for disability prevented with medical interventions alone. There are non-medical interventions proven to help individuals manage their arthritis, improve their health and well-being, and prevent further disability. During the statewide arthritis discovery meetings, persons living with arthritis — one after another — attested to the gains in their health status after participating in non-medical interventions such as arthritis exercise programs, warm water aquatics classes, and self-management courses.

The *National Arthritis Action Plan* recommends self-management education and exercise programs as having beneficial effects for people with arthritis. However, such interventions are not available in all Michigan areas, and clearly they are underutilized. Only 23 of Michigan's 83 counties have Arthritis Foundation Michigan Chapter program staff overseeing activities, thus limiting the extent of outreach available to persons with arthritis throughout the entire state. There are currently 76 sites for Arthritis Foundation aquatic exercise programs. However, only 16 of them are located outside of the territory of the Arthritis Foundation's four regional offices, all located in the lower peninsula. There are currently only 21 Arthritis Foundation land-based exercise sites in Michigan. Expansion of both aquatic and land-based exercise programs is needed to bring services to persons with arthritis throughout the state.

Even where arthritis exercise programs do exist, written and oral testimony collected at the arthritis discovery meetings confirmed that programs need to be made more accessible to persons with arthritis — offered at times and prices that encourage long-term participation. Attendees at Michigan's Arthritis Scientific Forum ranked increasing access to warm water aquatic exercise as a number one priority in helping persons with arthritis improve their quality of life.

"The hardest part of dealing with this disease is getting access to aquatic therapy programs where I can go on a continuing basis not just when I have big flare-ups. In my town, the aquatic programs are full, expensive and short-term."

Nan Schichtel, Grand Rapids area

## **Michigan Arthritis Action Plan**

In addition to exercise, the National Arthritis Action Plan also promotes the use of arthritis self-management programs. Research done with the Arthritis Foundation Self-Help Course showed that participants reported a 20 percent decrease in pain and a 40 percent reduction in doctor visits four years after completing the course. National arthritis experts at Michigan's Arthritis Scientific Forum strongly advocated for increasing self-management among persons with arthritis as a viable and low-cost public health intervention strategy. Michigan's arthritis interventions must also address primary prevention. Arthritis research literature and expert opinion from the arthritis scientific forum show that there are effective steps that can be taken to prevent osteoarthritis in the workplace and in schools. The importance of healthy weight control, occupational injury prevention, and sports injury prevention are public health messages that need to be disseminated in arthritis educational programs. By educating the public, employers and school administrators, some types of osteoarthritis and their subsequent disability can be largely prevented among Michigan citizens.

"I find warm water exercise invaluable. It is the closest thing to a panacea that you can get. What happens in this kind of exercise is that you're actually getting a massage from the water while you're exercising. Since I started doing warm water exercise, I have less need for naps and have 30-40 percent less pain than before I started."

Karen Nizol,  
Arthur's Place,  
southeast Michigan water  
therapy and exercise  
facility for people with  
arthritis



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<sup>1</sup>Lorig KR, Mazonson PD, Holman HR. Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. Arthritis & Rheum 1993;36(4):439-46.



## **Recommendations for Programs of Intervention**

### **Recommendation 3: Michigan should increase the geographic distribution, acceptability, and accessibility of effective exercise programs for citizens with arthritis:**

#### **3a. Warm Water Pool Exercise**

Michigan should double participation in warm water pool exercise programs proven to be effective for people with arthritis, such as the Arthritis Foundation Aquatic Program (AFAP), by 2005 (increasing from 3,422 to 7,744 participants per year by 2005). The following specific proposals are recommended to achieve this goal:

- ▶ **Increase the number and geographic distribution of available warm water pools:** The Arthritis Foundation should complete a statewide survey of warm water pools by 2001. Alliances should be initiated with public and private pool sites (including schools, community colleges, hotels, community recreation facilities, etc.) in which additional arthritis aquatics classes could be held, particularly in underserved parts of the state.
- ▶ **Recruit and train arthritis aquatic instructors:** Michigan should triple the number of trained arthritis aquatic exercise instructors by 2005, including students recruited from local exercise physiology and rehabilitation speciality college programs.
- ▶ **Recruit participants:** Michigan should promote the benefits of arthritis aquatic exercise among people with arthritis and also among health care providers and members of the public who might refer others. Efforts should also be made to offer classes at times that are more convenient for working persons.



Alice Lieffers, a child with JA, and arthritis aquatics instructor Tuovi Cochrane, who also has arthritis, in the Rockford Middle School pool, a regular site for warm water arthritis exercise classes.

### **3b. Land-Based Arthritis Exercise**

Michigan should at least double statewide participation in land-based arthritis exercise programs that are proven to be effective for persons with arthritis, such as the Arthritis Foundations's People with Arthritis Can Exercise (PACE) program by 2005. The following specific proposals are recommended to reach this goal.

- ▶ **Increase the number and geographic distribution of available sites:** Michigan should identify the location of potential new sites for arthritis land-based exercise programs and initiate alliances with public and private exercise facilities (including community colleges, community recreation facilities, etc.) to triple the number of sites and expand programs in all areas of the state.
- ▶ **Recruit arthritis land-based exercise instructors:** Michigan should triple the number of trained land-based arthritis exercise instructors by 2005, including students recruited from college exercise physiology and rehabilitation speciality training programs.
- ▶ **Recruit participants:** Michigan should actively promote the benefits of arthritis land-based exercise among people with arthritis and among health care providers and members of the public who might refer others.

"The greatest single thing Michigan can do if it seriously cares about addressing the pain and suffering of people with arthritis is to establish a statewide network of land and water-based exercise programs. My 20 years of experience as a rheumatologist has confirmed what national studies have shown, that people who exercise use less medication, have fewer physician visits, are less depressed, and have improved functioning."

Justus Fiechtner, MD, MPH  
Michigan State University

### **3c. Community Recreation/Wellness Programs**

The MACP, the Arthritis Foundation, Michigan Chapter, and the Michigan Recreation and Parks Association should work collaboratively to implement recommendations to increase participation of people with arthritis in existing community-based recreation and wellness programs.

Recommendations should include methods for:

- ▶ Educating coordinators and directors about the special needs of adults and children with arthritis.
- ▶ Identifying necessary equipment and building modifications to serve persons with arthritis.
- ▶ Obtaining resources for equipment and modifications needed.

**Recommendation 4: Michigan should initiate and distribute effective arthritis prevention programs for at-risk populations.**

**4a. School-Based Arthritis Prevention Program**

The MACP, the Michigan Department of Education, and associated partners should develop an educational program aimed at preventing joint injuries in children and young adults which predispose to later osteoarthritis (OA). This joint injury prevention program should be disseminated to physical education teachers, coaches, dance instructors and school staff. The program should include guidelines for adequate stretching and strengthening exercises as well as information about healthy weight control and the importance of complete and prompt treatment of injuries if they occur. Linkages should be made with the Michigan Department of Community Health sports injury prevention programs where applicable.

**4b. Employer Arthritis Prevention Program**

Michigan should initiate a new educational program for Michigan employers aimed at preventing joint injuries which predispose to osteoarthritis. Priority should be given, in distribution and training, to small companies first (those with fewer than 500 employees). Partners for this program could include the Michigan Economic Development Corporation, the Small Business Association of Michigan, and the Chamber of Commerce. This program should utilize educational materials discussed in recommendation #11.

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<sup>1</sup>Partners in this effort could include: Arthritis Foundation Michigan Chapter; Michigan Department of Community Health; Michigan Association for Health, Physical Education, Recreation and Dance; Governor's Council on Physical Fitness; Michigan Athletic Trainers Society; Institute for the Study of Youth Sports at Michigan State University; Michigan High School Athletic Association; and Michigan Exemplary Physical Education Curriculum.

"The Governor's Council on Physical Fitness has long embraced the policy that it should not hurt to play sports or to be physically active at work. The council has committed itself to promoting safe and injury-free activities. As the MAAP demonstrates, even relatively minor injuries can lead to the significant pain and disability of osteoarthritis in later life. The good news is that something can be done. We have effective injury prevention techniques and programs that can and should be disseminated to Michigan schools and work sites to help prevent injury-related osteoarthritis now."

Charlie Kuntzleman, EdD  
Chairman, MI Governor's  
Council on Physical Fitness

**Recommendation 5: Michigan should at least triple participation in arthritis self-management classes for persons with arthritis by 2005.**

(See also Recommendation #15.)

**5a. Train Self-Management Leaders**

Michigan should triple the number of trained program leaders for the *Arthritis Self-Help Course* (ASHC) by 2005. Among the new program leaders, there should be at least 100 individuals from community service agencies such as local health departments, Area Agencies on Aging, Centers for Independent Living, university health centers and Michigan State University Extension.

**5b. Bi-Lingual Program Leaders**

By 2003, Michigan should recruit at least 30 bilingual program leaders to facilitate the *Arthritis Self-Help Course* in settings where populations of non-English speaking people gather.

**5c. Web-Based Arthritis Self-Management Program**

MDCH should create a link between the new Michigan arthritis web site and the National Arthritis Foundation's web-based interactive self-management program called *Connect and Control: Your Online Arthritis Action Guide*.

#### 5d. Ongoing Support for Arthritis Self-Management Graduates

The MACP and the Arthritis Foundation Michigan Chapter should develop ways to maintain contact and support for graduates of the Arthritis Foundation self-management programs. The following strategies are recommended:

- ▶ **Arthritis Continuing Education Materials:** The MACP and the Arthritis Foundation Michigan Chapter should produce and distribute continuing education materials to be used by persons with arthritis after their participation in the self-management course.
- ▶ **Ongoing Arthritis Self-Management:** The MACP and Michigan research universities should pilot-test the feasibility of ongoing self-management groups in which participants eventually become the volunteer organizers and program leaders.



Freddie Shannon

"Programs like the *Arthritis Foundation Self-Help Course* need follow up. Sometimes people need to be reminded to do the things they know are good to do. It's hard to continue to do the work all by yourself. Sending a newsletter out to the *Self-Help Course* participants two or three times a year would help people with arthritis tremendously."

Freddie Shannon,  
Arthritis Awareness Urban Outreach Program  
Detroit, Michigan

### 5e. Recruitment of Class Participants

The MACP and the Arthritis Foundation should actively promote the benefits of participation in arthritis self-management programs to increase participation levels three-fold by 2005.

Studies show that arthritis self-management courses can lead to a reduction in pain, depression and disability among people with arthritis. A meta-analysis of 15 controlled psychoeducational studies in rheumatoid arthritis and osteoarthritis showed that, compared with control groups, persons with arthritis who were enrolled in courses had:

- 16 percent greater reduction in pain.
- 22 percent greater reduction in depression.
- 8 percent greater reduction in disability.

Source: Mullen, P.D., Laville, E.A., Biddle, A.K. & Lorig K. (1987) Efficacy of psychoeducational interventions on pain, depression, and disability in people with arthritis: a meta-analysis. J Rheum 14 (Suppl 15): 33-39.



# LIVING WITH ARTHRITIS IN MICHIGAN

Tuovi Cochrane

Tuovi Cochrane, a former Olympic gymnast, tries not to think about whether her hands and feet will be strong enough to get her out of bed in 10 years. The 59-year-old Rockford resident focuses more on how to make the best of her reality today. "You choose your attitude," says Cochrane. "There is a lot that people with arthritis can do." Cochrane, who was diagnosed with rheumatoid arthritis 12 years ago, has chosen to use exercise, a positive outlook, and outreach to others as her medicine.

Cochrane is not in denial about the reality of her arthritis or the pain that it causes. She just believes that people have to find what they can do and do it. Because of her arthritis, Cochrane can no longer teach university-level gymnastics or dance classes. Some days she cannot even walk because of her arthritis. However, she has found a way to use her exercise talents to benefit others. Cochrane teaches warm water exercise classes to people with arthritis at her local community pool.

It took Cochrane several years to admit that she would not be able to run, dance or teach gymnastics anymore after being diagnosed with rheumatoid arthritis at the age of 47. "I went through what everybody goes through," she said. "I was angry, depressed, and denied the whole thing. It took me years to accept that it's here to stay."

Cochrane, who has a husband and three children, said that she finally decided she had to go on living. So, she stopped fighting the arthritis so much. Cochrane has learned to live with arthritis by participating in the *Arthritis Self-Help Course*, which she now volunteers to facilitate. In addition, she reads inspiring books and magazines, such as *Arthritis Today*, to learn how other people cope with chronic conditions. She shares that wisdom with senior citizens at nursing homes.

Cochrane supports making arthritis programs more accessible and affordable — one of the key objectives of the MAAP. "So many people out there mistakenly think that they just need to live with the pain," she says.

Cochrane is well aware of the downward spiral that depression and feelings of helplessness can have upon a person's health. People can get out of the illness cycle by taking action. One of Cochrane's favorite actions is exercise. In addition to warm water exercise, Cochrane

bicycles several times a week, taking an hour and a half ride through the countryside. It is one exercise that she can still do because her ankle joints do not need to move.



Tuovi Cochrane

Another action Cochrane takes is changing her attitude. Instead of focusing on her pain, she tries to see herself as "okay," knowing that the pain will not last

forever. "If you believe you're okay, you'll feel pain less," Cochrane posits.

Cochrane has gained a great deal of wisdom from her arthritis. She has found personal growth and inner healing through her experience. "Pain is a great teacher," Cochrane says. "Are we listening to it, and are we learning to live fuller and more meaningful lives?" she asks. "The answer is up to us!"

"Enjoying living in spite of illness takes courage," she proclaims — with her words and her life.

## **C. Data and Research for Arthritis in Michigan**

### **Introduction and Statement of Problem:**

Very little specific data about arthritis exists in Michigan. At the Arthritis Scientific Forum, a panel of physicians, researchers and scientists from leading research organizations and universities throughout the country emphatically recommended that Michigan collect state-specific data that can be used to clarify the need for arthritis services and to document whether new arthritis initiatives are having their intended effects.

Michigan's arthritis efforts must be based on surveillance data and research about the risk factors, prevalence and impact of arthritis on the health, quality of life, employment and recreation of Michigan citizens. Carefully implemented surveillance can guide program design and distribution, help to target risk factor reduction programs, establish baseline and follow-up data for the evaluation of program efforts, and contribute to public and patient awareness efforts. This information is essential to guiding the implementation of every recommendation in this plan. Documentation of the disparate impact of arthritis on minority populations is also essential to ensure access to appropriate care for those in need.

Collaborating with national studies on the effectiveness of commonly-used programs and interventions will help to ensure that Michigan programs are based on proven models. In addition, the careful coordination of the Michigan Arthritis Action Plan implementation activities with clinical trials funded by government agencies and foundations would greatly benefit Michigan citizens with arthritis. Finally, given the significant number of Michigan citizens with arthritis who use alternative and complementary medicine approaches to reduce their pain, the compilation and dissemination of credible research information about the costs, risks and effectiveness of such approaches is necessary.



## **Recommendations for Data and Research**

### **Recommendation 6: The Michigan Department of Community Health (MDCH) should repeat the statewide Arthritis Behavioral Risk Factor Survey undertaken during FY 2001 at least every two years.**

Given the breadth of information needed and the limited opportunity for adding arthritis questions to the State-CDC Behavioral Risk Factor Surveillance Survey, MDCH should conduct a focused Arthritis Behavioral Risk Factor Survey every two years or, as was done in FY 2001, a combined osteoporosis and arthritis survey.

"Michigan's arthritis programs must be based on objective data that can help to substantiate their need, effectiveness, and efficacy. Periodic Behavioral Risk Factor Surveys are the essential public health surveillance tools needed to establish population-wide baselines, to assist in strategic planning of program interventions, and to track arthritis trends over time. Simply put, without valid survey data, there will be no way to determine where we are, where we have been, or where we are going."

MaryFran Sowers, PhD  
Professor of Epidemiology  
University of Michigan  
School of Public Health

### **Recommendation 7: The MACP should produce and widely distribute a State of Arthritis in Michigan Report at least once every three years, which would reflect the progress made in implementing the Michigan Arthritis Action Plan. Specifically, this periodic report should address:**

- ▶ Arthritis prevalence and trends in the state.
- ▶ Changes in health practices and services for arthritis.
- ▶ Programs and resources for persons with arthritis.
- ▶ Use of arthritis-related complementary and alternative medicine services and remedies.
- ▶ Use of a broad range of arthritis-related medical and allied health services.
- ▶ Use of arthritis self-management programs.
- ▶ The cost of arthritis in Michigan.

The MACP should issue the first report no later than 24 months after the start date of the partnership and distribute its findings to organizations such as the Arthritis Foundation Michigan Chapter and local health departments, where it can be readily used as a resource guide.

“The testimony received at the Michigan Arthritis Action Plan regional discovery meetings revealed that there were significant information gaps among providers, patients, and the public. A widely-distributed periodic report will ensure that Michigan citizens and community programs have the latest and most accurate information about this devastating condition.”

Barbara Adams, MD  
Director of Pediatric Rheumatology  
University of Michigan Health System

**Recommendation 8: The MACP, in partnership with Michigan universities engaged in medical research, should collect Michigan-specific data on less common forms of arthritis.**

Working through or in collaboration with Michigan universities engaged in medical research, Michigan should establish and support ongoing data bases for the collection of information and surveillance data about the nature, extent, treatment and availability of support services for arthritic conditions for which little or inadequate Michigan-specific information exists (e.g. lupus, scleroderma, juvenile arthritis and fibromyalgia).

“Establishing and maintaining specific arthritis data bases at Michigan’s universities engaged in medical research and at medical schools is one of the most cost-effective ways of filling the information gaps regarding the less prevalent but often highly costly forms of arthritis.”

Maureen Mayes, MD  
Professor of Internal Medicine  
Wayne State University/Hutzel Hospital

**Recommendation 9: Michigan should seek to coordinate, to the extent possible, Michigan arthritis initiatives with national and regional arthritis research and evaluation efforts.**

**9a. Quality of Care Standards for Arthritis**

The MACP and its partners should work to ensure that Michigan is pro-active in providing its citizens and health care providers with the latest and most accurate information regarding quality of care standards for screening, treatment and rehabilitation for arthritis patients. In addition, the MACP and its partners should seek to collaborate with and contribute to national efforts in establishing quality of care standards for arthritis.

**9b. Complementary and Alternative Care for Arthritis**

The MACP should monitor and support national and regional efforts to document the use, effectiveness and risks of complementary and alternative care for arthritis in Michigan.

These efforts will require specific outreach by those responsible for implementation of the MAAP to national and regional research, evaluation and surveillance studies.

“It is essential that Michigan keep informed about newly-emerging effectiveness research and, where appropriate, participate in national and regional studies. Michigan planning efforts and program initiatives can directly benefit from state-of-the-science information about the effectiveness of program approaches and health care practices.”

Dr. Robert Meenan, MD, MPH, MBA  
CDC National Arthritis Planning Group

# LIVING WITH ARTHRITIS

Nancy Kiel

Ever since Nancy Kiel, Grand Rapids, developed arthritis, she has been helping others to gain from her experience. Kiel, 53, a registered nurse at Steelcase Inc., struggled terribly to understand her own arthritis when she was diagnosed 12 years ago. She was dissatisfied with her treatment, feeling that her rheumatologist was not using an aggressive enough approach. She saw her hands changing shape in front of her eyes and was increasingly using canes and splints to function at work and home. Her whole life was changing, and she was scared.

She became so interested in finding out as much as she could about arthritis that she arranged for speakers to come to Steelcase, to help educate herself and her coworkers. "My motive was selfish," Kiel says sheepishly. She admits that she was looking for answers for herself.

Yet, Kiel's quest for answers not only benefitted her, but her co-workers and her community as well. In collaboration with the Arthritis Foundation, Michigan Chapter, Steelcase hosted its first program, "Taking Charge of Your Arthritis," followed by programs on different types of arthritis, such as rheumatoid arthritis, osteoarthritis, fibromyalgia, and arthritis-related hand and wrist disorders. The programs were very popular, drawing about 80-100 persons per session.

From those first programs, Kiel gained a wealth of knowledge about arthritis. She found a new rheumatologist, who gave her a more aggressive treatment program. The progression of her symptoms slowed. Seldom having to use splints or canes, Kiel could once again move freely. Kiel did not stop educating herself, however. She took the *Arthritis Foundation Self-Help Course* and arranged to have the class at Steelcase.

Kiel says she was amazed at what she learned in the *Arthritis Foundation Self-Help Course*. "Even though I am a nurse, the classes you take in nursing school don't give you the information about arthritis that you get from this course," she said. Kiel says the knowledge and support

she gained from others in the course was invaluable. She has been an advocate for arthritis education ever since.

Other arthritis-related educational programs have been brought on site for Steelcase's 9,000-plus employees and the surrounding Grand Rapids community. They include coping with chronic illness, pain management, stress and relaxation, diet and arthritis, and proper exercise techniques. Spouses and loved ones

have been encouraged to attend the programs, as chronic illness affects the whole family.

Kiel says that she is fortunate to work for a company that has been so caring and flexible.

Steelcase Inc.,

the world's largest manufacturer of office furniture, has helped with advertising, meeting space and audiovisual equipment to support the programming.

Kiel now works in the Steelcase Wellness Department part-time. This allows for some flexibility in her schedule to accommodate her physical needs and appointments. Kiel says that Steelcase takes a very progressive approach toward accommodating people with medical conditions and work restrictions.

"I think most people with medical conditions actually work harder when they are feeling good. They know there are times when they do not feel their best, but they still want to be productive employees," Kiel says.

She supports the MAAP's goal of reducing barriers to employment for people with arthritis. Kiel says that her employer has found a way to utilize the talents of people with arthritis, and "I know other employers can do it, too."



Nancy Kiel

## **D. Public Awareness, Communication and Education**

### **Introduction and Statement of Problem:**

Arthritis affects nearly one in six people and one in three families,<sup>1</sup> reaching all segments of the population, including children in schools, employees in work sites, patrons at senior centers and residents of communities. Even more individuals are touched by arthritis through their daily interactions and relationships with those who have arthritic conditions. Consequently, raising public awareness — about the impact of arthritis; the importance of early diagnosis; as well as strategies to prevent, treat and manage arthritic conditions is a primary goal of both the *National Arthritis Action Plan* and the *Michigan Arthritis Action Plan*. Public awareness and education are necessary to dispel widespread misunderstanding about arthritis and to link people to credible, accurate and useful information resources. Through public awareness and education, Michigan can begin to make inroads into changing behaviors and creating environments that will allow the state to achieve the goals of arthritis prevention, management, and reduction of disability.

Despite increasing data about the burden of arthritis in both the state and the nation, it is evident that awareness of the issue in Michigan is not widespread. Testimony at all three arthritis regional discovery meetings held throughout the state documented that the general public in Michigan does not recognize arthritis as a significant health problem. Individuals with arthritis at the discovery meetings expressed concern that many of their co-workers and neighbors did not understand their condition and the daily challenges they face due to their arthritis. The MAAP Steering Committee identified the need for widespread arthritis education and urged that arthritis prevention and management strategies be an important communication priority for Michigan's citizens. The committee agreed that accurate and consistent arthritis-education messages could be communicated through various media channels. They also determined that, in doing so, many of the educational messages tailored to persons with arthritis would also be appropriate for the general public.

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<sup>1</sup>*National Arthritis Action Plan*. (1999). pp.31

## **Recommendations For Public Awareness, Communication and Education**

**Recommendation 10: Michigan should implement an educational campaign for the general public to increase basic understanding of arthritis, its prevention, treatment and management. The scientific and patient care messages in this campaign should be defined by the MACP and should be consistent with those developed by the CDC. (See also Recommendation #13.)**

### **10a. Essential Information for the Public**

The MACP, MDCH, University of Michigan Multipurpose Arthritis and Musculoskeletal Diseases Center, and other appropriate partners should inform the public about the nature and course of arthritis as well as treatments, interventions and resources available to help people with arthritis. Essential information includes: a core set of facts about arthritis that every person should know; the availability of a toll-free hot line and the number; how to obtain a directory of resources for arthritis; an increased variety of condition-specific information; the seriousness of arthritis; and the benefit of interventions. (See also Recommendation #14b.)

### **10b. Multiple Channels**

The MACP should use multiple channels to disseminate information about arthritis. These channels could include:

- A Michigan-specific arthritis web site
- Cable television stations
- Michigan Model for Comprehensive Health Education
- Media spots
- An arthritis speakers bureau
- Outreach programs to underserved and minority groups
- Existing networks of information and referral providers
- Arthritis Foundation toll-free line
- The Michigan's Exemplary Physical Education Curriculum
- The Governor's Council on Physical Fitness, Health and Sports
- Michigan Association for Health, Physical Education, Recreation and Dance
- The Michigan Recreation and Park Association

"It is exciting to envision the implementation of the public awareness recommendations of the MAAP. When implemented, an individual seeking information about arthritis will be able to access a wide spectrum of Michigan-specific arthritis information, referrals and educational resources."

Angelia Mosely-Williams, MD  
Hutzel Hospital, Division of Rheumatology

**Recommendation 11: Michigan should develop educational materials about arthritis and other musculoskeletal conditions specifically for employers and work sites.** *(See also Recommendation # 4b.)*

**11a. General Arthritis Awareness Education**

The MACP should ensure that work site educational materials are developed to increase general awareness of and sensitivity to arthritis among employers and employees. Arthritis awareness materials for work sites should cover a core set of facts about arthritis every person should know and other topics listed in Objective 11c.

**11b. Mutual Benefits of Providing Arthritis-Related Accommodations**

The MACP should ensure that educational materials are developed to increase awareness about worksite changes and conveniences that improve facilities, policies and conditions for persons with arthritis. Educational materials should address:

- ▶ Information about the mutual employer - employee benefits of providing persons with arthritis flexible scheduling and other accommodations that help employees to best manage their condition and thus maintain their productivity. (Allowing flexibility in work schedules for medical treatments and interventions can reduce overall absence due to illness.)
- ▶ Examples of work-related accommodations for persons with arthritis that maximize productivity yet minimize stress and trauma such as more frequent short breaks throughout the day.

### 11c. Benefits of Work Site Arthritis Prevention

The MACP should make available to employers educational materials that demonstrate the value of arthritis prevention and adequate arthritis treatment and management for both employers and employees. Educational materials should include:

- ▶ The potential for preventing or reducing the severity of osteoarthritis through minimizing repetitive joint trauma and encouraging healthy weight control.
- ▶ The opportunity to prevent repetitive joint injuries, which can lead to osteoarthritis, by supplying ergonomic equipment for employees when appropriate.
- ▶ The likely decrease in workers' compensation costs due to workplace wellness activities.
- ▶ The overall net benefit of providing treatment and self-management for persons with osteoarthritis (and other forms of arthritis) early on, thus reducing later disability, complications, pain and health care costs.

To the extent possible, the above arthritis workplace educational materials should be incorporated with the MDCH Worksite and Community Health Promotion Program, the Governor's Council on Physical Fitness and other programs that focus on employee wellness.

"Caring about arthritis issues makes good business sense. Steelcase believes that employer-based arthritis prevention education programs can have a significant impact on the health of workers. Failure to address these issues can result in more site injuries, increased health care costs, and more frequent sick leave."

Marshall Beard  
Manager, Benefits  
Steelcase Incorporated,  
Grand Rapids



**Recommendation 12: In collaboration with MSMS and other health provider agencies, the MACP should organize arthritis professional development seminars for health planners, community agencies, and regional area networks, etc. (See also Recommendation # 13.)**

These seminars will educate on the prevalence, health burden, and societal costs of arthritis as well as give information about effective arthritis interventions that have been shown to reduce pain, disability and health care costs.

“Over the years, Michigan has been fortunate to have an enlightened public health response to a variety of health issues. A key element in this success has been a close working relationship among researchers, public health officials, health providers, and state and local decision-makers. This tradition bodes well for the effective implementation of the MAAP. ”

David Fox, MD  
Chief of Rheumatology  
University of Michigan Health System

# LIVING WITH ARTHRITIS IN MICHIGAN

Janet Weilbaeher

If you have ever bitten into something cold, you know the sharp pain that it causes between your eyes. That is one of the ways East Lansing resident Janet Weilbaeher describes the pain she feels from having scleroderma. Scleroderma is an autoimmune disease affecting the skin, joints and internal organs. Weilbaeher, 48, says her pain varies from sharp and radiating to a constant achiness. "Each day that I wake up, I am not sure what the pain will be like," Weilbaeher says.

Despite her daily body pain, Weilbaeher still manages to live an active life with her family and within her community. Weilbaeher has learned alternative ways to have fun with her grandchildren without moving her body so much. She is not able to run with them or to lift them in her arms. However, she has found a creative game to play with them. She takes her small hands, which have become stiff and curled under, makes them into "the claw" and makes the kids laugh. She says, "I try to use a lot of humor with my condition."

The hardest part of having scleroderma, Weilbaeher says, is other people's lack of understanding about what she is going through.



Janet her husband, Al

"Even my husband can't understand what I am feeling." Just walking a block is difficult for Weilbaeher, who used to walk six miles several times a week. People think that just because she looks fine, that she feels fine, she says. Once Weilbaeher was even questioned for using a handicapped parking space at the grocery store. She says she is glad that the Michigan Arthritis Action Plan addresses public awareness of arthritis so that family members, friends, neighbors, co-workers and the general public will show more sensitivity to people like herself.

Weilbaeher was diagnosed with scleroderma five years ago when she was working as a medical and dental claims examiner. She was experiencing achiness and pain in her arms and hands. After being misdiagnosed twice and having an unnecessary surgery, Weilbaeher finally found out that she had systemic scleroderma. "I had never heard the word scleroderma before," Weilbaeher said.

During the two years following the diagnosis, the arthritis in Weilbaeher's hands, feet and knees accelerated. "The things that I had taken for granted before suddenly became difficult," she said. Activities like brushing her teeth, buttoning her clothing, and holding pens became nearly impossible due to her claw-shaped hands. Weilbaeher learned how to cope with many of her new limitations through occupational therapy. Her therapists provided her with grips for pens and toothbrushes that made them easier to hold. Occupational therapy was very helpful, Weilbaeher says. She says she wishes that her insurance would pay for long-term or on-and-off again occupational therapy.

Despite the difficult adjustment period after her diagnosis, Weilbaeher says she feels like her life is normal again. She has accepted that she must do certain activities either differently or more slowly than she used to. "And some things you just can't do," she said. She has even learned to accept that. "Just think of the things you can do. It makes you appreciate life a lot more."

## **E. Education and Communication Strategies for People with Arthritis and their Families**

### **Introduction and Statement of Problem:**

From the testimony provided by persons with arthritis during the development of the Michigan Arthritis Action Plan, it is abundantly clear that there are limitations in the variety, availability, accessibility and utility of educational programs for persons with arthritis and their families throughout the state. People with arthritis found the Arthritis Foundation programs to be very helpful, but there were still gaps in resources for persons with the less common arthritic conditions such as lupus, fibromyalgia and scleroderma. Persons on fixed incomes or with limited financial resources found affordable programs scarce. Parents of children with arthritis pleaded for more support groups for both parents and children. All persons with arthritis asked that materials providing self-management instruction, information about specific conditions and location of resources for assistance be much more widely disseminated throughout the state, including such locations as public libraries and schools. The recommendations in the MAAP call for realistic strategies to meet these identified needs.

### **Recommendations for Education and Communication Strategies for People with Arthritis and their Families**

**Recommendation 13: The MACP, the Arthritis Foundation Michigan Chapter, MDCH, the University of Michigan Multipurpose Arthritis and Musculoskeletal Diseases Center, and other involved agencies should empower people with arthritis with knowledge about their arthritis conditions.** *(See also Recommendation #5.)*

#### **13a. Quality and Availability of Statewide Arthritis Education for People with Arthritis**

The MACP should ensure the availability of high-quality education for people with arthritis in Michigan, including:

- Access to self-management programs.
- In-home education programs for home-bound people with arthritis.
- Programs which serve a variety of diverse groups including minorities and groups distinguished by language, geographic locale, culture, lifestyle or other characteristics.

### 13b. Condition-Specific Arthritis Educational Materials

The MACP and Michigan health agencies, in conjunction with the Arthritis Foundation, should increase the variety, quantity and availability of condition-specific informational materials for persons with arthritis and their families. The forms of arthritis for which materials are currently insufficient, in the judgement of the MAAP Steering Committee, include at least the following:

- Fibromyalgia
- Scleroderma
- Lupus
- Juvenile arthritis

### 13c. Information about Arthritis Orthotic Devices and Surgical Procedures

The MACP should establish a committee of physical therapists, occupational therapists, orthopedic surgeons, podiatrists, researchers and rheumatologists to help draft educational materials, in conjunction with the MACP, for persons with arthritis about the potential usefulness of orthotic adaptive equipment and surgical procedures.

“We know that little accurate information is currently in the hands of individuals challenged by less common forms of arthritis. Filling these knowledge gaps can help to ensure that thousands of Michigan citizens with fibromyalgia, scleroderma, lupus, and juvenile arthritis will get the help they need to take control of their arthritis.”

Oretta Todd, PhD, RN  
Arthritis Awareness Urban Outreach  
Arthritis Foundation Michigan Chapter

## **Recommendation 14: The MACP, the Arthritis Foundation, MDCH, and other involved agencies should increase statewide awareness of resources available for persons with arthritis and their families.**

*(See also Recommendation 10b.)*

### 14a. Arthritis Foundation Toll Free Information Service

The Arthritis Foundation should increase, by 50 percent, use of the AF toll free number by 2003, by increasing publicity about the phone number, disseminating information to information and referral providers about the phone number and services available, and increasing the capacity to handle calls (staffing, phone lines, etc.).

**14b. Statewide Directory of Arthritis Resources**

The MACP and Michigan health agencies should develop and widely disseminate a bi-annual directory of resources for arthritis. The first issue should be printed and distributed to local public health agencies by 2001.

**Recommendation 15: The MACP, the Arthritis Foundation, MDCH and other involved agencies should conduct targeted, cost-effective educational outreach to persons with arthritis and their families in communities that are underserved.**

**15a. Statewide Arthritis Speakers Bureau**

The MACP should develop, maintain, and widely promote a statewide speakers bureau to address community groups. The speaker's bureau should be most aggressively promoted among underserved groups.

**15b. Minority and Underserved Groups**

The MACP should develop and implement a plan to recruit participants among minority and underserved groups for arthritis educational programs, increasing participation in educational programs by at least 10 percent annually.

**15c. Support and Education Groups for Persons with Arthritic Conditions**

Michigan should provide support and education groups for people with arthritic conditions, including the training and utilization of experienced persons with arthritis or arthritis-related conditions as peer leaders for these groups. Such programs should include the Arthritis Foundation Michigan Chapter's support and education groups for arthritis or fibromyalgia.

### 15d. Cost-Effective Arthritis Educational Programs

The MACP and other partners should expand the availability of educational programs for persons with arthritis through linkages with:

- Public health providers
- Michigan State University Extension
- American Association for Retired Persons
- Parks and recreation programs
- Senior citizens centers
- Aging networks
- Faith communities



Arthritis Awareness Urban Outreach program representatives, Oretta Todd and Freddie Shannon, promoting the *Arthritis Foundation Self-Help Course* in Detroit-area churches.

"Over half of all people over the age of 65 are affected by arthritis, and the majority of them have not received information about managing their condition. To close this gap, Michigan's aging network must continue to build partnerships with health care providers and community-based arthritis education and exercise programs."

Lynn Alexander  
Director, Michigan Office of  
Services to the Aging

"Empowering the 1.5 million men, women and children who have arthritis by providing accurate information and by encouraging self-management skills will help to reduce the burden of arthritis statewide. People with arthritis can be prepared to be more effective partners in their own health care."

Michelle Glazier  
President/CEO  
Arthritis Foundation, Michigan Chapter



# LIVING WITH ARTHRITIS IN MICHIGAN

Erin and Lynne Kyser

Some parents hope their children can easily tie their shoes before kindergarten. Lynne Kyser, a Grand Rapids-area mother, hopes that her daughter Erin will reach that milestone before college. Erin, 17, has juvenile rheumatoid arthritis. As a result, it is difficult for her to move her hip, back, wrist, knee and neck joints. They are stiff and sometimes immobile.

Erin would have fewer limitations today if she had received better care for her arthritis when she was first diagnosed at the age of six. Erin suffered permanent joint damage that could have been prevented had she been participating in physical therapy and received more appropriate medical care.

For four years, Erin was placed on differing drug treatments, none of which helped to arrest her symptoms. The soreness and achiness in her joints only continued to get worse. The Kysers did not know where to turn for help.

Finally answers started to come when Lynne Kyser contacted the Arthritis Foundation. She was given information about pediatric rheumatologists, other kinds of arthritis treatments and a camp for kids with juvenile arthritis. That is when Erin says her life began to turn around. Erin attended her first juvenile arthritis camp that summer at the age of 10. There she connected with a pediatric rheumatologist, Dr. Barbara Adams, who introduced Erin to physical therapy. Aside from the new treatment, Dr. Adams also helped educate Erin about her arthritis.

Dr. Adams made all the difference, Erin says. Before Dr. Adams, Erin had been told to take her pills without a lot of explanation as to what her arthritis was. "Dr. Adams knew how to explain what was going on with me in words that I could understand. It was awful not knowing anything about my condition all those years," Erin said.

Erin's self-esteem rose dramatically after she began to understand her arthritis. Her morale improved also after she attended the Arthritis Foundation JA camp. At camp, young people just like her were living successfully with arthritis. Some of them were even more physically limited than she was. Erin said she and her parents left the camp realizing that they did not need to have a "pity party" for her anymore and that she was actually pretty lucky.

Erin continued to see Dr. Adams and was placed on a more aggressive treatment regime, including physical therapy and stretching exercises.

Lynne Kyser supports the MAAP's objectives to encourage greater education for parents of children with juvenile arthritis. "I would have checked out more options had I known about them," Kyser said. She now coaches other parents of children with arthritis through a mentor program at the University of Michigan Pediatric Rheumatology Center.

Erin still feels angry about her treatment experience. She regrets not being more mobile throughout her school years. However, she is taking control of her arthritis now. She attends physical therapy, makes special arrangements with her teachers to get accommodations in the classroom, and is reading literature about how to take care of her arthritis when she goes to college.



Erin Kyser

Despite Erin's physical limitations, she has managed to remain quite active in school. Aside from playing the piano, flute and saxophone, she marches in the school band, acts in school plays, mentors other students, and is an officer in the National Honor Society. Even though she has not been able to play sports in high school, she says

she has learned to be proud of herself — a lesson many people do not learn until after college.

Erin says that the MAAP should encourage educational support groups, so people with arthritis will know that they are not alone. In addition, she urges that doctors talk to children about their arthritis so they will know what is happening to them.



## **F. Communication Strategies for Health Professionals**

### **Introduction and Statement of Problem:**

Health professionals receive education at two levels. First, students in academic programs preparing for their professions receive information included in their basic curricula. Content included in a basic professional curriculum is the responsibility of the academic institution. It is well-defined, with criteria to ensure that material is current and scientifically sound. The second level of professional education occurs after a provider begins practice. Every few years, health professionals update their knowledge and skills through continuing education courses or programs. Testimony at all three regional arthritis discovery meetings and at the scientific forum identified an urgent need for arthritis education of providers at both levels.

With regard to pre-professional academic education, persons with arthritis voiced frustration that primary care physicians often failed to understand their day-to-day problems. An effective approach to supplying physicians with this basic understanding was described by faculty from the University of Michigan Medical School, where persons with arthritis serve as patient educators to teach clinical skills to medical students. These trained educators report very positive responses from the medical students. Health care providers attending the scientific forum voiced their support for extending the patient educator clinical skill-building model to all health care provider curricula. Ideally, a core arthritis curriculum for all health care professions would be available, although the details to be included in basic educational programs would vary by profession.

With regard to continuing education, medical and allied health providers at the regional discovery meetings, scientific forum, and on the steering committee reported that participation in continuing medical education programs is increasingly difficult with competing time constraints placed on providers. Providers in rural areas reported that there are few opportunities to obtain specialized continuing education locally. Development of a statewide communication infrastructure to deliver continuing, arthritis- related professional education was strongly supported. Providers who participated in the development of the Michigan Arthritis Action Plan agreed that such an infrastructure should be designed to enable providers to participate in continuing education activities without interrupting their practice schedules.

There was universal support from the several health care disciplines who participated in the discovery meetings and scientific forum for multidisciplinary continuing education programs on arthritis, with presentations from a variety of provider specialties. Providers and persons with arthritis agreed that the team approach to continuing education should increase the probability that providers would recommend comprehensive management regimens for persons in their care. Health care experts at the scientific

forum urged that new channels for delivery of high-quality, professional education be attempted and evaluated to ensure accessibility and acceptability.

A well-educated network of providers with state-of-the-science knowledge of arthritis is greatly needed in Michigan.

### **Recommendations for Communication Strategies for Health Professionals**

#### **Recommendation 16: Michigan must greatly enhance the availability of accurate arthritis-related information and skill development for health care providers during their pre-professional academic training.**

##### **16a. Rheumatology Training**

The MACP, in conjunction with the four Michigan medical schools and all training programs for allied health professions, should ensure that substantial rheumatology education, including exposure to persons with arthritis, is available to students.

##### **16b. Expansion of the Patient Partner Instructor Program**

The MACP should work to greatly expand the Pharmacia Corporation Patient Partner Instructor program, currently in place at the University of Michigan, which raises the sensitivity of health care providers to the special needs of people with arthritis. The program should be incorporated into the core curriculum of all medical schools and all training programs for allied health professionals in Michigan (i.e. PT, OT, pharmacy, nursing, nutrition/dietetics, psychology/counseling, massage therapy and other complementary and alternative specialization programs).

"I am a patient partner instructor and have severe arthritis. In this role, I provide insights to health care professionals about what it is like to have this challenging condition. As a dedicated patient partner instructor, I offer valuable living lessons in arthritis for health care professionals, health care students, and people with arthritis. Through both scientific knowledge and personal experience, I can share those things that have helped me to live well with my arthritis."

Nancy Brown  
Patient Partner Instructor,  
Pharmacia Corporation  
Arthritis Foundation Volunteer

**Recommendation 17: Michigan should greatly increase participation in accurate, science-based arthritis-related continuing education by health care providers in the state.**

**17a. Communication Infrastructure**

The MACP should develop a statewide communication infrastructure, using all available technology to create interfaces among the following groups of health care providers and their professional associations:

- |   |   |
|---|---|
| ◆ Physical therapists                   | ◆ Recreational therapists   |
| ◆ Occupational therapists               | ◆ Physical health educators   |
| ◆ Primary health care providers         | ◆ Podiatrists and orthotists  |
| ◆ Pediatricians                         | ◆ Exercise and fitness professionals                                |
| ◆ Geriatricians                         | ◆ Licensed alternative and complementary health practitioners       |
| ◆ Rheumatologists                       | ◆ Nutritionists, dieticians   |
| ◆ Pediatric rheumatologists             | ◆ Public health professionals (educators, nurses, program managers) |
| ◆ Psychiatrists and counselors          | ◆ Massage therapists  |
| ◆ Orthopedic surgeons and hand surgeons | ◆ Chiropractors   |
| ◆ Nurses, nurse practitioners           |   |
| ◆ Physician assistants                  |   |
| ◆ Pharmacists and pharmacologists       |   |

"My previous doctor did not take my complaints about my arthritis seriously. He just told me that I was getting older. Luckily, I didn't take that for an answer. I hurt, and I wanted something that I could do to help myself. I have a doctor now who listens to me and who understands my arthritis pain. I am glad that I did not accept old age as an excuse for unbearable pain."

Janet Whitaker, 67  
Detroit



Janet Whitaker

#### 17b. Continuing Education Topics

The MACP should ensure that by 2005, Michigan health care providers will have the opportunity to conveniently access accurate, interesting continuing education programs about arthritis topics such as:

- The complex variation of presenting conditions.
- The need for individualized treatment plans and information for patients.
- Pain management and the psychological effects of chronic pain.
- Strategies for strength training.
- Active and passive range of motion exercises.
- Self-management strategies.
- In-home services for people with arthritis who are homebound.

"There are at least three important reasons for enhancing continuing education for health professionals: 1) there is increasing information about the etiology and treatment of arthritis, 2) there is new evidence about effective patient care, and 3) there are scientifically-proven self-management programs readily available for people with arthritis."

Dorothy Nelson, PhD  
Division of Rheumatology  
Wayne State University



## **SECTION III: IMPLEMENTATION**

### **A. Priorities for Early Implementation**

The *Michigan Arthritis Action Plan* Steering Committee spent months working to develop an arthritis plan that would become a reality for Michigan citizens. In order that these recommendations serve as more than words in a booklet, the steering committee and their representative organizations commit to the following implementation time line:

#### October 1 - December 30, 2000

- Establish the MACP.
- Complete a survey of the warm water pools in Michigan.
- Begin networking with organizations that may play a role in implementing the plan.

#### January 1 - March 31, 2001

- Organize and hold the first two meeting of the MACP. Set dates and times for the rest of the years' meetings.
- Begin distributing the plan to public health agencies, health professional organizations, community agencies and libraries.
- Implement and establish ongoing support for a Michigan-specific arthritis web site.
- Develop a strategy for implementing recommendations 4, 5 and 6, listing resource and personnel needs to carry out these arthritis programs statewide.

#### April 1 - June 30, 2001

- Hold a press conference to announce the release of the plan.
- Continue with distribution of the plan.
- Continue to network with organizations that may play a role in implementing the recommendations.

#### July 1 - September 30, 2001

- Develop a list of second-year priorities for the implementation of the MAAP.
- Compile data from the BRFSS.
- Continue networking with organizations that may play a role in implementing the recommendations.
- Design an arthritis educational campaign consistent with the media guidelines set forth by the CDC.
- Complete the first State of Arthritis in Michigan report.

### **B. Next Steps (to be determined by the MACP)**

## **Appendix A: Michigan Arthritis Action Plan Steering Committee**

### **Co-Chairs:**

- David Fox, M.D., Chief, Division of Rheumatology, Department of Internal Medicine, University of Michigan Health System
- Michelle Glazier, President/CEO, Arthritis Foundation Michigan Chapter

### **Members:**

- Barbara Adams, M.D., Director of Pediatric Rheumatology, University of Michigan Health System
- Nancy Brown, Volunteer, Arthritis Foundation Michigan Chapter
- Ellen Clement, M.S.W., Public Health Director, Washtenaw County Public Health Department
- Justus Fiechtner, M.D., M.P.H., Medical Director, Fiechtner Research
- Larry Gruppen, Ph.D., Director, Office of Educational Resources and Research, Department of Medical Education, University of Michigan
- Carla Guggenheim, D.O., Rheumatologist
- Dawn Hafeli, Vice President for Programs, Arthritis Foundation Michigan Chapter
- Marshall G. Katz, M.D., Chairman, Medical Director's Committee, Michigan Association of Health Plans
- Nancy Kiel, R.N., Steelcase Incorporated
- Charles Kuntzleman, Ed.D., Chairman, Governor's Council on Physical Fitness, Health and Sports
- Maureen Mayes, M.D., Professor of Internal Medicine, Division of Rheumatology, Wayne State University
- Joseph McCune, M.D., Professor of Rheumatology, Department of Internal Medicine, University of Michigan Health System
- Richard McLellan, Attorney, Dykema Gossett
- Angelia Mosely-Williams, M.D., Division of Rheumatology, Hutzel Hospital
- Dorothy Nelson, Ph.D., Division of Rheumatology, Wayne State University/Hutzel Hospital
- Helene Rosen, P.T., Michigan Physical Therapy Association
- Tina Skerske, O.T.R., Michigan Occupational Therapy Association
- MaryFran Sowers, Ph.D., R.D., Professor of Epidemiology, School of Public Health, University of Michigan
- James Taborn, M.D., Midwest Arthritis Center
- Oretta Todd, Ph.D., R.N., Arthritis Awareness Urban Outreach, Arthritis Foundation Michigan Chapter
- John Tower, D.O., Michigan Osteopathic Association
- Joseph Weiss, M.D., Michigan State Medical Society
- Carol Wruble, M.S., Nutrition Specialist, Michigan State University Extension Service



## **Appendix B: Acknowledgments**

The Michigan Department of Community Health, the Arthritis Foundation Michigan Chapter and the University of Michigan Multipurpose Arthritis and Musculoskeletal Diseases Center would like to thank numerous individuals who helped in the development of the *Michigan Arthritis Action Plan* at the regional arthritis discovery meetings and the arthritis scientific forum.

### **Steering Committee**

The 25 individuals who served on the *Michigan Arthritis Action Plan* Steering Committee, listed in Appendix A, provided invaluable insight into the medical and scientific aspects of arthritis and spent many hours helping to carefully develop the recommendations in this plan.

### **Regional Arthritis Discovery Meetings**

#### **Michigan Citizens:**

The MAAP could not have been created without the input of the numerous Michigan citizens with arthritis and their health care providers, who voiced their concerns through personal correspondence and at statewide arthritis discovery meetings. They contributed an abundance of practical wisdom, experience and knowledge to the *Michigan Arthritis Action Plan*.

#### **Local Site Hosts:**

Local site hosts for the regional discovery meetings generously coordinated arrangements for the meetings and helped with publicity.

- Grand Rapids: Barbara Terry, M.S., Deputy Director, Kent County Health Department and Barbara Hawkins Palmer, M.A., Healthy Kent 2010 Coordinator, Kent County Health Department; John Reaves, PT, Director of Physical Therapy, Mary Free Bed Hospital and Rehabilitation Center
- Troy: Rosemarie Rowney, R.N., M.P.H., Manager Health Division, Oakland County Health Division and Marcia Graham, B.S.N, R.N., Oakland County Health Division; Ron Beford, Vice President, Corporate Communications and Information Systems, Greater Detroit Area Health Care Association
- Gaylord: Elizabeth Gertz, Executive Director, North Central Council of the Michigan Health and Hospital Association; Gerald Chase, M.P.H., Administrator and Nancy Bottomley, M.S., R.N. Director, Adult Health and Aging Services, Northwest Community Health Agency

### **Michigan Arthritis Scientific Forum**

National and state arthritis experts also contributed to the development of the plan at Michigan's Arthritis Scientific Forum, providing key recommendations and critical feedback.

#### **Consultants:**

- Robert Meenan, M.D. , M.P.H., M.B.A., Centers for Disease Control National Arthritis Planning Group; Dean, Boston University School of Public Health

## ***Michigan Arthritis Action Plan***

- Marc Hochberg, M.D., Head, Division of Rheumatology and Clinical Immunology, University of Maryland
- Alfred Franzblau, M.D. Associate Professor of Occupational and Environmental Medicine, University of Michigan School of Public Health
- Steven Goldstein, Ph.D., Henry Ruppenthal Family Professor of Orthopedic Surgery and Bio-engineering, University of Michigan Medical School
- Timothy Laing, M.D., Associate Professor of Rheumatology; Associate Chair of Clinical Programs, Department of Internal Medicine, University of Michigan Health Systems

### **Financial Sponsor:**

Pfizer, Inc. partially supported the discovery meetings and scientific forum through an unrestricted educational grant.

## **Staff**

### ***Michigan Department of Community Health:***

- Jean Chabut, M.P.H., Director, Division of Chronic Disease and Injury Control
- Jan Christensen, J.D., M.S.W., Manager, Violence Prevention Section
- Jean Friend, M.P.A., R.D., Supervisor, Michigan Office of Services to the Aging
- Carol Garlinghouse, M.S.N., R.N., Nurse Manager, Division of Chronic Disease and Injury Control
- Karen Petersmarck, Ph.D., M.P.H., Consultant, Division of Chronic Disease and Injury Control
- Cheryl Schott, M.P.H., Centers for Disease Control Prevention Specialist
- Rosemary Wilkins, Secretary, Violence Prevention Section

### ***Michigan Public Health Institute:***

- Holly Makimaa, Writer, Program Consultant
- Loretta Neville, M.S.A., R.N., Senior Health Consultant

### ***Arthritis Foundation Michigan Chapter:***

- Barbara Spreitzer-Berent, Senior Director of Public Education

### ***University of Michigan:***

- Norma Elias, Program Coordinator, Multipurpose Arthritis and Musculoskeletal Diseases Center
- Carol Cottrell, Administrator, Division of Rheumatology

## Appendix C: Participating Organizations

### **Organizations that played an active role in the development of the *Michigan Arthritis Action Plan***

- Arthritis Foundation Michigan Chapter
- University of Michigan:  
Department of Internal Medicine,  
Division of Rheumatology  
Department of Medical Education,  
School of Public Health,  
Multipurpose Arthritis and  
Musculoskeletal Diseases Center
- Lupus Foundation
- Sparrow Hospital:  
Rheumatology Center  
Office of Educational Resources &  
Research
- Office of Services to the Aging
- Michigan Association of Health  
Plans
- Steelcase Inc.
- Corporate Medical/Wellness
- Governor's Council on Physical  
Fitness, Health and Sports
- Michigan Public Health Institute
- Wyoming Senior Services, Kent  
County Parks and Recreation  
Department
- Local Health Departments (four  
represented)
- The Senior Alliance
- Detroit Medical Center, Gerontology
- United Auto Workers
- Charlevoix Area Hospital
- Northern Michigan Hospital
- Area Agencies on Aging (three AAAs  
represented)
- Wayne State University/Hutzel  
Hospital: Division of Rheumatology
- Scleroderma Foundation
- Dykema Gossett Law Firm
- Michigan Physical Therapy  
Association
- Michigan Occupational Therapy  
Association
- Midwest Arthritis Center
- Michigan Osteopathic Association
- Michigan State Medical Society
- Michigan State University Extension  
Service
- Mary Free Bed Hospital and  
Rehabilitation Center
- Center for Physical Rehabilitation
- Greater Detroit Area Health Council
- Detroit Parish Nurse Network
- American Podiatric Medicine  
Association, Michigan
- Arthritis Awareness Urban Outreach  
Program
- Birmingham Area Senior Service  
Center
- Children's Hospital of Michigan,  
Rheumatology Division
- North Central Council of Michigan  
Health and Hospital Association
- Michigan Department of Career  
Development, Michigan  
Rehabilitation Services

## Appendix D: Arthritis Resources in Michigan

### Arthritis Foundation Michigan Chapter (AF)

#### Staff:

- 22 full-time employees and one part-time employee located at four regional offices
- 3,000 AF volunteers

#### Services:

- Regional offices in four locations directly serve 23 of Michigan's 83 counties. The other 60 counties are served through the state headquarters.
- A toll-free hotline (1-800-968-3030) is available weekdays from 8:30 a.m.-4:30 p.m.
- The National Arthritis Foundation web site ([www.arthritis.org](http://www.arthritis.org)) includes links to Michigan-specific program information.
- *Arthritis Today* magazine is mailed to AF members six times a year.
- The state newsletter, *Spectrum*, is sent to Michigan chapter members quarterly.
- Arthritis support and education groups are available in 21 locations, and fibromyalgia support and education groups are available in 22 locations.
- Michigan has 98 active *Arthritis Foundation Self-Help Course* leaders and 43 active *Fibromyalgia Self-Help Course* leaders.
- *The Arthritis Foundation Aquatics Program* is available at 80 warm water pool sites.
- The AF has certified 68 instructors for the land-based *People With Arthritis Can Exercise class*.
- The AF offers ongoing public education. In 1999, 140 public speaking presentations reached 9,943 people, and 160 educational exhibits reached 16,834 people.
- Arthritis education programs are regularly offered for health care professional organizations.
- The AF partners with the American Juvenile Arthritis Organization (AJAO) in:
  - (1) Sponsoring families to attend the national AJAO conference each year.
  - (2) Providing educational and support programs for families of children with JA.
  - (3) Promoting Juvenile Arthritis Awareness week.
- The Arthritis Awareness Urban Outreach Program offers the *Arthritis Self-Help Course* and informational programs at urban churches in metropolitan Detroit.

## **Lupus Foundation**

### **Staff:**

- Two full-time and three part-time employees
- 350 volunteers

### **Services:**

- One statewide office (800-705-6677) is open 9:30 a.m. to 4:30 p.m., Monday through Friday, in St. Clair Shores.
- The foundation maintains a Michigan web site ([www.mi.lupus.org](http://www.mi.lupus.org)).
- Sixteen support groups are available.
- An annual lupus conference focusing on medicine and research is held every May in Detroit.
- One additional meeting is convened per year usually with a medical focus.
- The chapter's newsletter, *Lupus Copes*, is published six times a year, and the national Lupus Foundation newsletter is available four times a year.
- Help-lines run by volunteers in Alpena and Detroit offer information and assistance to callers. Call (800) 705-6677 for more information.

## **Scleroderma Foundation**

### **Staff:**

- One part-time independent contractor and one part-time secretary
- About 240 volunteers

### **Services:**

- The office is open with telephone service 20 hours a week (800-716-6554). Call backs are made to people who call during off hours and on weekends.
- The foundation maintains a Michigan web site ([www.miscleroderma.org](http://www.miscleroderma.org)).
- Eight support groups are available statewide.
- One major scleroderma conference is held each year in the fall. Three or four other meetings take place per year, each with a medical theme.
- Video tapes from national and Michigan meetings are available to borrow.
- A Michigan newsletter is sent to members quarterly, and a national newsletter is available on request.

## **Michigan Department of Community Health (MDCH): The Michigan Arthritis Initiative**

### **Staff:**

- Contract manager for the Michigan Arthritis Initiative (funded by the Centers for Disease Control): 0.15 FTE
- Five professional staff of the Division of Chronic Disease and Injury Control with partial responsibility for the Michigan Arthritis Initiative
- Contractual staff: 0.5 FTE (funded by the Centers for Disease Control)

## ***Michigan Arthritis Action Plan***

### **Services:**

- Staff manage a \$60,000 federal grant from the CDC to reduce the burden of arthritis.
- Statewide arthritis surveillance is conducted through a telephone survey and collection of health data.
- MDCH staff facilitate the work of the Michigan Arthritis Collaborative Partnership.
- The Children's Special Health Care Services Plan Division provides gap insurance for children with chronic conditions, including childhood arthritis.

### **Michigan Arthritis Collaborative Partnership**

The Michigan Arthritis Collaborative Partnership was formed in 2001 to oversee implementation of the Michigan Arthritis Action Plan (MAAP). The group is comprised of 20 concerned citizens who are affected by arthritis and professionals who care for people with arthritis. A scientific committee oversees medical and research-related issues. Issue-specific working committees address high priority objectives in the MAAP.

### **University of Michigan Multipurpose Arthritis and Musculoskeletal Diseases Center**

The University of Michigan Multipurpose Arthritis and Musculoskeletal Diseases Center is a multidisciplinary, multidepartmental research and education program funded by the National Institutes of Health. It is responsible for developing state-of-the-art research on musculoskeletal diseases and for treating persons with arthritis. While the center's administration is based in the Department of Internal Medicine's Division of Rheumatology, its staff and participants are actively involved in other university departments, schools, and colleges.

### **Staff:**

- 144 staff members and participants including approximately 128 doctoral-level (Ph.D. or M.D.) senior members drawn from five schools and colleges, 16 departments, and six divisions

### **Services:**

#### **Biomedical Research**

- Major research programs related to arthritis and musculoskeletal diseases have been developed within the education, epidemiology, and health services areas.
- Research proposals focus on understanding the basic mechanisms operative in rheumatoid arthritis, systemic lupus erythematosus, osteoarthritis, and other rheumatic diseases.

#### **Education/Community/Health Services**

- Research is conducted in the areas of professional education, health services and epidemiology.
- The center integrates basic scientific advances into the clinical care of patients with rheumatic diseases.
- The center participates in activities of charitable foundations and government.

## ***Michigan Arthritis Action Plan***

### **Professional Education and Training**

- Training is provided for students, physicians, and allied health professionals.
- A fellowship program prepares M.D.s and Ph.D.s for productive, independent careers in rheumatic-disease-related fields of research such as immunology, biochemistry, or molecular genetics.
- The center oversees clinical rotations in rheumatology for 35 to 40 junior- and senior-year medical students.
- Rheumatology-related lectures, seminars, clinical experience, and laboratories are provided to medical students at all stages of their undergraduate academic careers.
- Internal medicine residents receive training on all the rheumatology clinical services.
- The center provides continuing education for practicing physicians.

### **Health Care Services and Facilities**

- Six hundred patients each year are admitted to the center's eight-bed arthritis Inpatient Unit. Patients are evaluated, treated, and given care by a multidisciplinary team comprising physicians, students, nursing staff, and allied health professionals.
- A rheumatology consultation service is provided for approximately 450 patients per year at the University of Michigan Medical Center and at the Ann Arbor Veteran's Administration Medical Center.
- Patients are also treated at the Ambulatory Clinic. Last year, there were over 12,000 patient visits to the clinic.

## **Michigan State University School of Human Medicine**

### **Services:**

- During the first and second year of medical school, students participate in the Longitudinal Patient Experience program. Students see a patient with a chronic illness eight times. Afterward, the students meet in small groups to discuss their patients' varying cases, some of which may include arthritis.
- Second-year medical students take a neuromuscular-skeletal course that covers the clinical aspects of arthritis. They learn about arthritis through textbooks, self-study and a clinical exam.
- During the third- and fourth-year clerkships, students have varying hands-on experience with arthritis based upon the number of persons they encounter with the condition.

## **Wayne State University**

### **Services:**

- A state and national scleroderma registry is maintained.
- The medical school offers a residency program in rheumatology.
- Rheumatology health care is available through Hutzel Hospital.



## **The Pharmacia Corporation Patient Partner Instructor Program**

Pharmacia Corporation funds a program to help educate health care professionals, medical students and people with arthritis about the scientific and practical aspects of having arthritis. In Michigan, patient partner instructors are extensively trained to teach the medical aspects of arthritis and are sponsored by a physician instructor at the University of Michigan. Patient partner instructors share their personal experience of what it is like to live with arthritis. They give practical tips on how to cope with arthritis and how to live full, high-quality lives.

## **Arthur's Place**

Arthur's Place is a fitness facility specifically designed for persons with arthritis in Plymouth, Michigan.

### **Services:**

- Arthur's Place is open Monday through Saturday with evening hours on weekdays (734 254-0500).
- Personalized health assessments and fitness plans are tailored to the needs of persons with arthritis.
- A web site ([www.arthursplace.com](http://www.arthursplace.com)) is accessible.
- Warm water individual tanks for bicycling and paddling are available as well as an indoor swimming pool.
- On-site *Arthritis Foundation Self-Help Courses*, aquatic courses, and land-based exercise courses are offered.
- Educational lectures occur onsite regularly.
- An informational library provides books and audio-visual tapes. Trained staff offer exercise assistance to persons with arthritis as well as give advice on activities of daily living.

## **School-Based Services for Children with Arthritis**

If limitations from arthritis affect a student's ability to learn and benefit from his/her education, the school district is required by federal law to provide the accommodations and/or services needed to allow him/her to fully benefit from the educational process and reach his/her maximum potential. Such laws as the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act (ADA) protect students' rights in school. The "Early Intervention" Law of 1986 (P.L. 99-457) extends the age of eligibility for school-based special education and related services to children as young as three and as old as 21. Because arthritis can cause developmental delays, children are sometimes eligible for early intervention services.

## **The Center for Yoga**

The Center for Yoga, located in East Lansing, Michigan (517-333-9883), offers beginning-level yoga classes specifically designed for persons with fibromyalgia and arthritis. Class sessions focus on yoga postures that gently stretch the body, breath awareness techniques that help to reduce stress and enhance energy, and deep relaxation strategies that give the body overall rest.

## **Area Agencies on Aging**

### **Services:**

- Sixteen Area Agencies on Aging (AAAs) provide services to seniors throughout Michigan. To locate an Area Agency on Aging, see [www.mdch.state.mi.us/mass](http://www.mdch.state.mi.us/mass) or call (517) 373-8230.
- Medicaid Waiver Program: The Medicaid waiver program is a comprehensive, community based, in-home services program designed specifically for persons who are deemed medically eligible for nursing home placement. Services are provided through the waiver program to allow persons to stay in their homes. Services include: Home delivered meals, in-home and out of-home respite care, homemaker services, personal care supervision, transportation, medical equipment and supplies, counseling services, chore services, environmental modifications, training, and home health aide. Fourteen of the 16 AAAs offer the Medicaid Waiver Program.
- Transportation Services: Some AAAs coordinate transportation services in counties and townships such as:
  - ▶ Redford Township: Dial-a-Ride
  - ▶ Wayne, Westland, Garden City and Inkster: Nankin Transit Commission
  - ▶ Suburban Mobility Authority for Regional Transportation (SMART): operable in many communities. Check with your local Agency on Aging.
- Michigan Emergency Pharmaceutical Program for Seniors (MEPPS): Low-income seniors (65 and over), with prescription costs in excess of 10 percent of their monthly income, are eligible to apply for vouchers three times a year to cover the full cost of a 30-day supply of their prescriptions. For information on this program, see [www.mdch.state.mi.us/mass](http://www.mdch.state.mi.us/mass) or call (517) 373-8230.

## **American Red Cross: Local Chapters**

### **Services:**

- Some local chapters provide home delivered meals, rides to medical appointments, caregiver education and support groups, friendly visitors, Lifeline , hospital and nursing home volunteers, and fuel assistance.
- A web site ([www.redcross.org](http://www.redcross.org)) is available to find out what services local chapters offer.

## **Dean C. Burns Community Education Center**

The Dean C. Burns Community Education Center is a community health facility affiliated with Northern Michigan Hospital in Petosky, Michigan, that provides some services for persons with arthritis.

### **Services:**

- A lending library (231-487-4900) with resources on arthritis is open Monday through Friday 8:30 a.m. to 5:00 p.m.
- Magazines and newsletters from the Arthritis Foundation are available to read.
- The center hosts annual fall and spring events with guest speakers on fibromyalgia.

## **Health Care Providers in Michigan (2000 data)**

### **Providers:**

- 135 rheumatologists
- Three sites for pediatric rheumatology
- 6,315 physical therapists
- 3,574 occupational therapists
- 488 orthopedic surgeons
- 751 podiatrists
- 1,020 massage therapists in the American Massage Therapy Association, Michigan Chapter

### **Training Programs:**

- Four medical schools (University of Michigan, Wayne State University, and two at Michigan State University School of Human Medicine and School of Osteopathy)
- Two residency programs in rheumatology (University of Michigan and Wayne State University)
- Five occupational therapy schools
- Six physical therapy schools

## **Limitations of services available in Michigan**

### **Geographic Distribution:**

There are numerous inequalities in the geographic distribution of health care services available for persons with arthritis. While many services exist in Michigan, large regions of the state have few arthritis health care specialists. Most arthritis providers are clustered around large metropolitan areas — with fewer services and programs available in the many rural areas of the state. For instance, the Upper Peninsula has only three of the 135 practicing rheumatologists in the state. Some Michigan residents have to travel up to a day's time just to see a rheumatologist, especially if a pediatric rheumatologist is needed. Parents of children with juvenile arthritis sometimes forego services that could prevent or minimize later disability for their children — simply because of geography.

## ***Michigan Arthritis Action Plan***

Arthritis support groups and exercise programs are also unevenly available throughout the state. (See Appendices E, F and G). Arthritis exercise programs and support groups help persons with arthritis to maintain their physical and mental health. Yet, these helpful interventions are virtually non-existent in much of rural Michigan, especially in the Upper Peninsula. Even where they do exist in the lower peninsula, the number of programs is insufficient to serve the number of persons with arthritis.

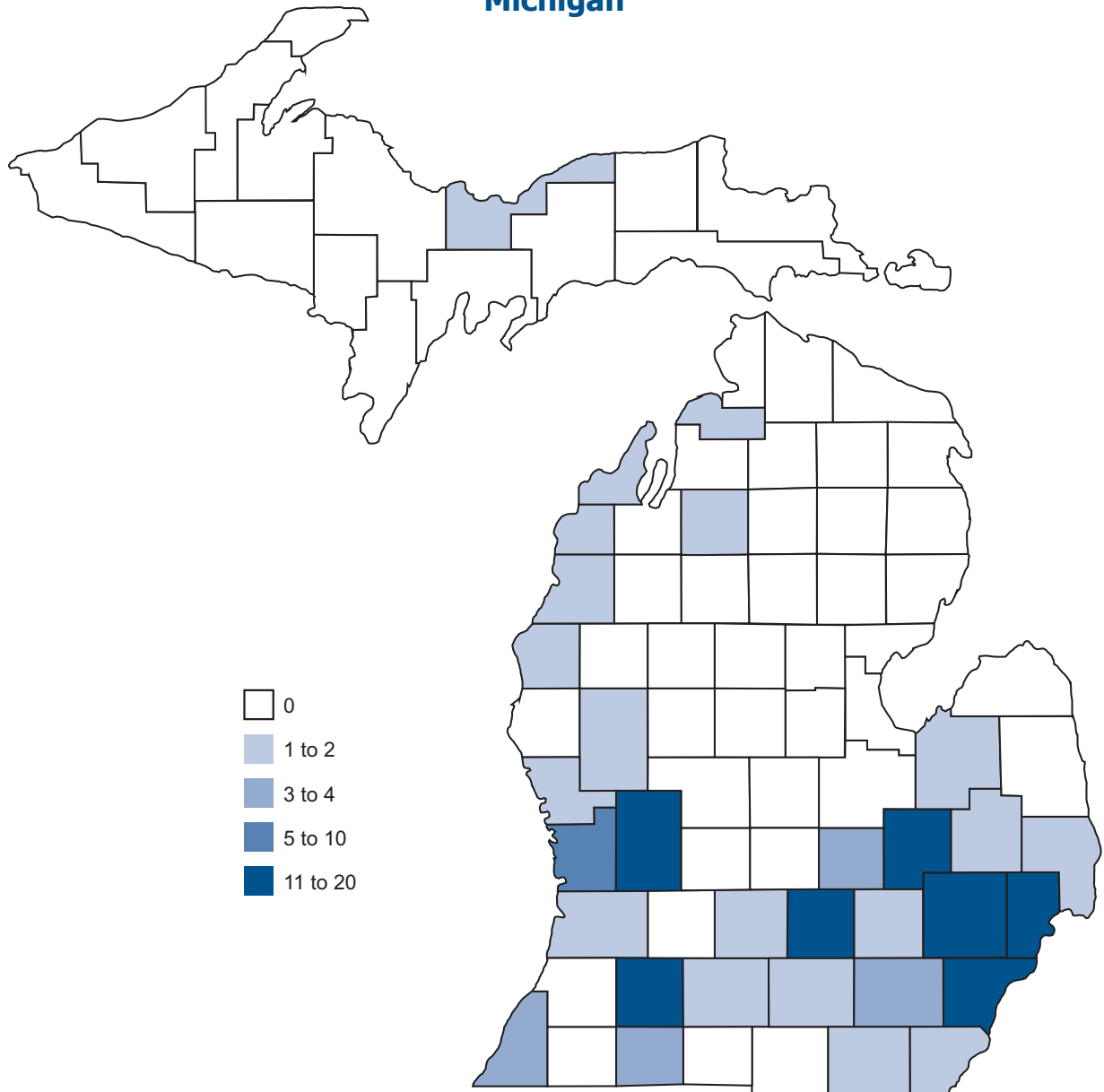
### **Quality of Care:**

The quality of arthritis medical treatment and care appears to be uneven in Michigan. Numerous persons at the statewide arthritis discovery meetings reported that they felt their primary health care physicians did not take their arthritis pain seriously. Some persons even stated that they were not allowed a referral to see a rheumatologist for their conditions. Yet, other persons with arthritis have found physicians who understand that arthritis can be treated and managed. Clearly the arthritis expertise of physicians varies greatly in the state.

The quality of treatment from allied health professionals (e.g. physical therapists, occupational therapists and other rehabilitation specialists) also appears to be uneven in Michigan. Individuals with arthritis who gave input for the MAAP stated that the quality of their allied health care treatments has ranged from poor or harmful to excellent or beneficial.

## Appendix E: Arthritis Exercise Classes\*

Number of Leaders per County  
Michigan

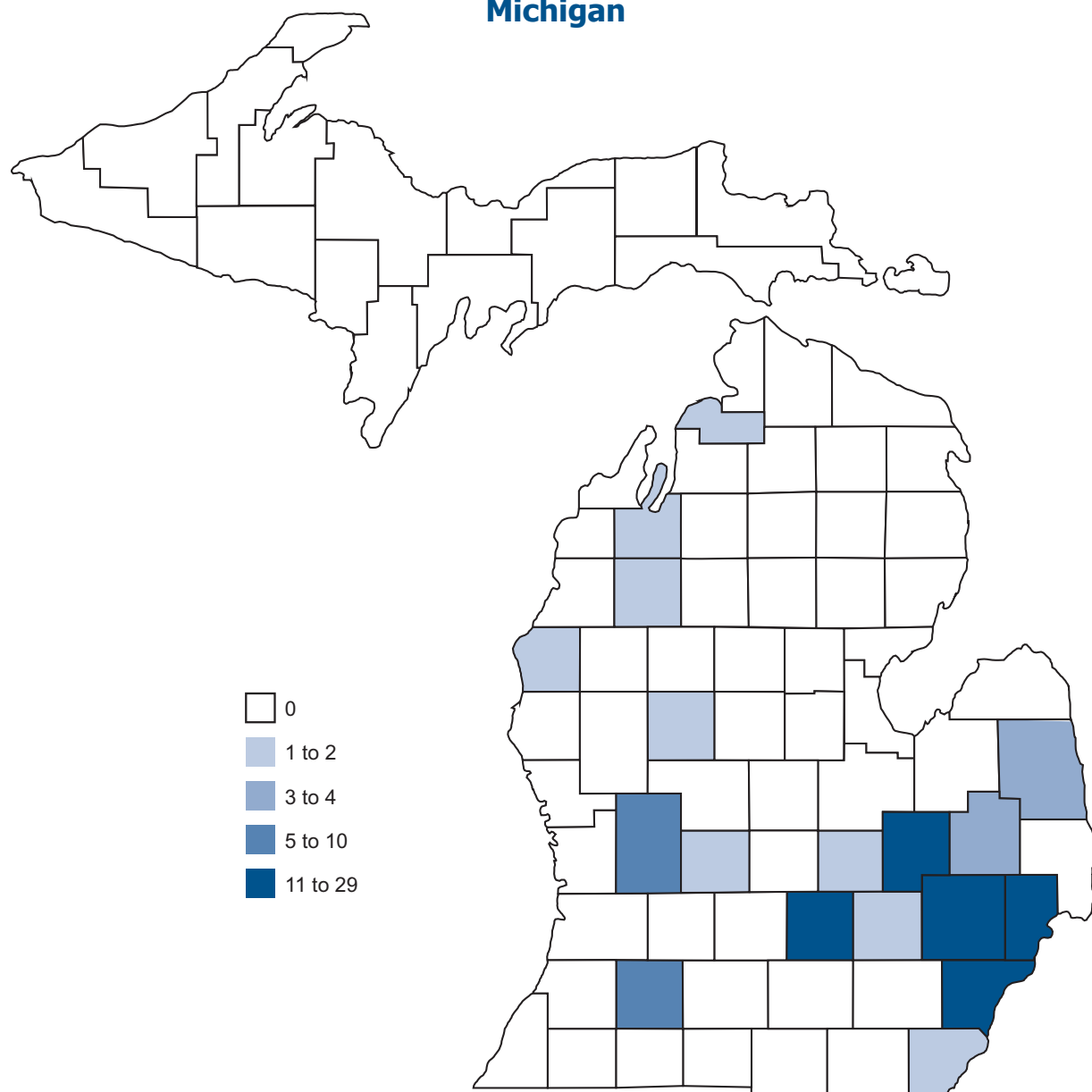


Updated November, 2000

\*Includes the Arthritis Foundation Aquatics Program (AFAP), held in warm water pools, and the land-based People with Arthritis Can Exercise (PACE) Program. For schedule and site information, call the Arthritis Foundation Michigan Chapter, 800-968-3030.

## Appendix F: Arthritis Self-Help Course

## Number of Leaders per County Michigan



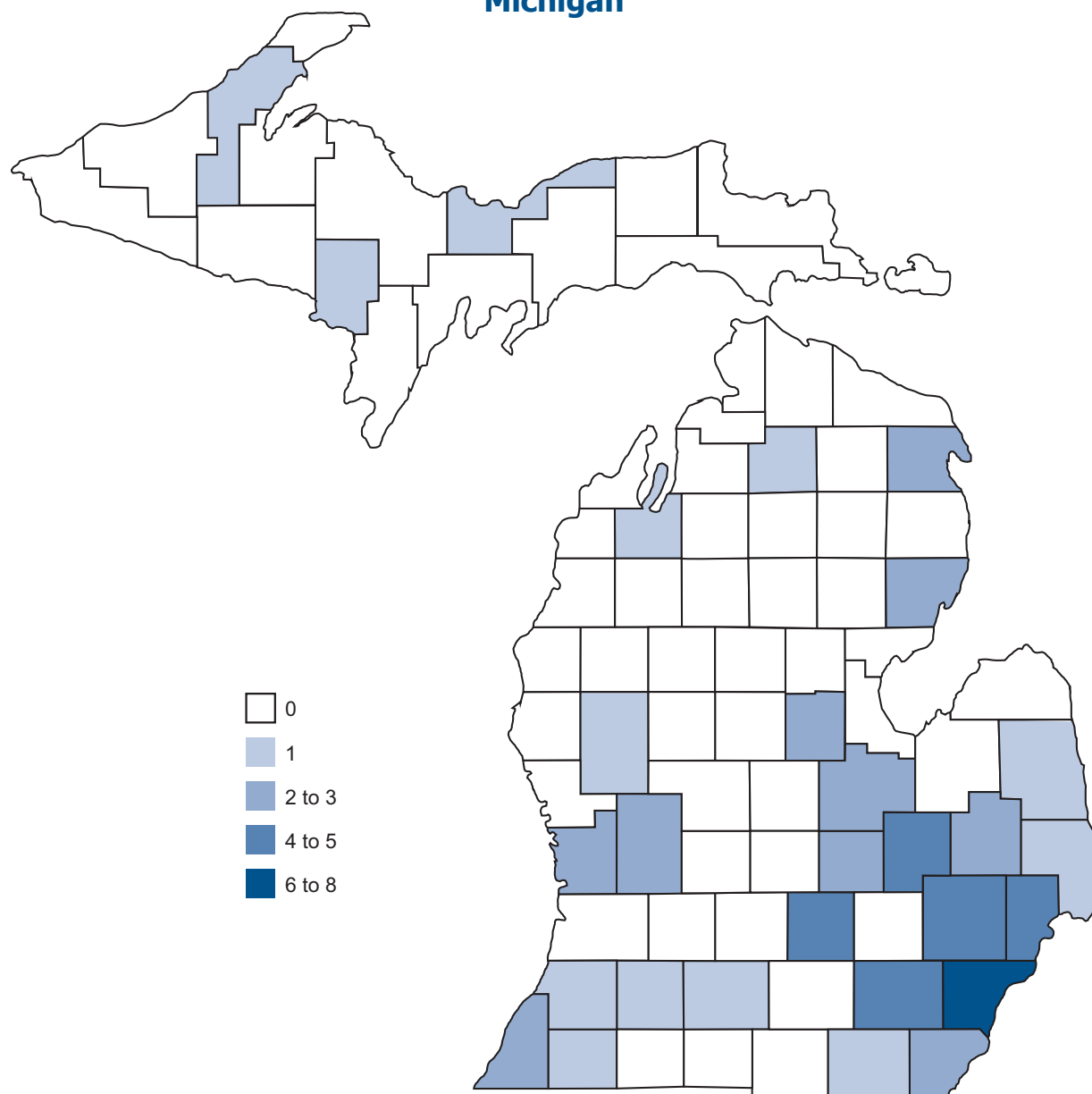
**Updated November, 2000**

For schedule and site information:  
Call the Arthritis Foundation Michigan Chapter, 800-968-3030.

## Appendix G: Arthritis-Related Support Groups

### Number of Groups per County

## Michigan



**Updated November, 2000**

Includes arthritis and fibromyalgia support groups sponsored by the Arthritis Foundation Michigan Chapter (800-968-3030), lupus support groups sponsored by the Lupus Foundation (800-705-6677) and scleroderma support groups sponsored by the Scleroderma Foundation.



*Michigan Department  
of Community Health*



*John Engler, Governor  
James K. Haveman, Jr., Director*

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